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COMMUNICATION DISORDERS AND STROKE IN AFRICAN-AMERICAN AND OTHER CULTURAL GROUPS:

MULTIDISCIPLINARY PERSPECTIVES AND RESEARCH NEEDS

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Preface

On May 19-20, 1997, the National Institute on Deafness and Other Communication Disorders (NIDCD) and Howard University sponsored a conference to address the need for increased research on communication disorders and stroke in African-American and other cultural groups. The conference was supported by the Office of Research on Minority Health.

The purpose of the conference was to identify existing knowledge, which is limited and scattered throughout the literature in several disciplines, and to articulate a research agenda for NIDCD and the scientific community. The conference provided researchers and clinicians in communication sciences and disorders, neurology, psychology, and neurolinguistics an opportunity to present overviews of existing research as well as identify areas of research need.

The demographics of the United States population are changing. Present estimates suggest that by the middle of the twenty-first century the majority of the country's citizens will be members of minority groups—groups with varied languages, health risk factors and cultural experiences. Research on the speech and language of special populations is needed in order to identify multicultural factors relevant to the appropriate assessment and treatment of speech and language disorders.

Current data indicate that African Americans have more than twice the risk of stroke compared to their Caucasian counterparts. Many of these individuals who survive a stroke have residual speech or language problems (aphasia) that could be improved through treatment.

For many African Americans, as well as other cultural groups including Hispanic Americans, Native Americans and Asian/Pacific Islander Americans, the best evaluation instruments would be those that are sensitive to language differences. In addition, treatment which strives to restore pre-stroke communication competencies should take these differences into account.

This monograph contains the presentations of most of the conference participants. Topics include epidemiology, assessment and management of sequelae of stroke, cultural variables, and contemporary issues in acute stroke management and assessment. Also, issues related to environmental and cultural influences on rehabilitation and research, and issues regarding quality of life are included.

The Need For Mad Scientists

Lorraine Cole, Ph.D.

Keynote Address

Thank you, Dr. Anderson. Good morning, honored guests, distinguished speakers, ladies and gentlemen. It is an honor and a privilege for me to be here. You might have expected me to begin by saying something like that; many opening speeches begin that way. But, in my case, I could not be more sincere. It is truly an honor and a privilege. In fact, I would go so far as to say it is a thrill for me to be here to participate in the wedding ceremony of NIDCD and Howard University.

Many long-term ASHA members present may remember that I spent much of my adult professional life as the Director of the Minority Concerns for the American Speech-Language-Hearing Association before moving on to other pursuits. My staff and I dedicated those years to promoting the recognition of multicultural issues in communication disorders as being much more than rhetorical discussions about "Ebonics" and bilingualism. Critical clinical and research issues affecting racial and ethnic minorities span the entire range of speciality areas in the professions of speech-language pathology and audiology—from aphasia to cleft palate, fluency disorders, language acquisition, voice disorders, hearing disorders and so on.

Our efforts toward that end were very gratifying in two arenas. Within the academic arena, there is now a heightened recognition of the importance of infusing multicultural clinical and research information throughout the curriculum. Efforts to ensure the training of culturally competent clinicians are now institutionalized in many training programs and is even a requirement for program accreditation in communication disorders. And, within the clinical arena, among practicing clinicians, there is now a higher level of recognition of the need to continually improve ones knowledge base and skill to better serve diverse populations.

Unfortunately, the scientific arena has been the last bastion yet to be convinced that communication disorders in minority populations merit serious, large scale study. So, I have very good reason to be thrilled to participate with Howard University and NIDCD to address research issues of communication disorders and stroke in African American and other cultural groups.

Historical Barriers

There has been a long history of confusion, misunderstanding, and malfeasance associated with the topic of research conducted within the African American community. There has been a lot of research conducted on African Americans that exemplify doing the wrong thing, the wrong way, for the wrong reasons. Just three days ago, President Clinton symbolically put long-overdue closure on one of the greatest examples of scientific exploitation in American history perpetrated against African Americans in the name of medical science. He apologized, on behalf of the U.S. government, to the survivors and the families of what has come to be known as the Tuskegee experiment.

In that study, the researchers took the view that 399 African American men were laboratory animals rather than human subjects. They took advantage of their poverty condition, using the promise of free food and free medicine to lure them into participating. They purposefully misused culturally-rooted terminology to deceive the subjects, referring to their syphilitic condition merely as "bad blood," which was a term used generically to refer to unspecified ailments. They were subjected to excruciating painful clinical protocols. And, known treatments—lifesaving treatments—were withheld. The study, which was supposed to last six months, extended for forty years, ending in 1972.

With the enactment of the 1974 National Research Act, creating a National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, safeguards exist to ensure that such a travesty never recurs. We can, now, more confidently encourage African Americans to volunteer for biomedical and behavioral research studies. However, we continue to struggle against the effects of the legacy of that study. Because African Americans continue to be distrusting of the scientific process, the results of most clinical trials are skewed because of an underrepresentation of African Americans. Subsequently, treatment protocols, health statistics and national health policies are promulgated based on those racially biased clinical studies which further deny African American communities of the benefit of valid scientific advances.

In addition to such historical factors, there are many perceptual, social, political and paradigm issues that remain as barriers to major research efforts directed at the health problems of African Americans.

PERCEPTUAL BARRIERS

I will describe a major perceptual barrier. There has been almost a concerted resistance to the notion that communication disorders in minority populations merit serious study. I, personally, experienced this resistance when I began proposing dissertation research ideas in the hallowed halls of Northwestern University in the mid 1970s. Many university faculty members across the country presently report that research on cultural aspects of communication disorders are not acceptable as part of their qualifications for promotion to tenure. It has been difficult to convince new panels of funding agencies that the study of communication disorder in multicultural populations is worthy of major funding support.

This resistance has been due, in large part, to the perceptual dichotomy between basic science (i.e., biomedical and behavioral science) and everything else that is referred to as science. Among basic scientists, there is an appearance of scientific elitism in which phrases like social science and political science are viewed as oxymorons. In a figurative sense, basic science is considered Science with a capital "S," while all other sciences seem to be considered "lowercase."

Within the professions of Communication Disorders, the issues affecting minority groups originally focussed upon cultural and linguistic differences, specifically, social dialects and bilingualism. This narrow focus has led to the association of multicultural research topics with social science. Even though it has been clearly established that multicultural issues encompass every aspect of the professions, the stigma associated with the earlier narrow focus persists.

POLITICAL BARRIERS

I would like to describe a *political* issue that has been of concern to me relative to minority health objectives. Issues of discrimination against specific groups of people have come to be regarded as legal or Civil Rights issues. Civil Rights clearly fall within the domain of political science. However, within the biomedical research arena, Civil Rights templates have become superimposed on measures of minority health status.

Title VI of the 1964 Civil Rights Act is one of the landmark products of the Civil Rights Movement. It was enacted to prohibit the expenditure of federal funds on activities and programs that discriminate on the basis of race, color or national origin. The legislation encompasses all operations of entities, agencies, businesses, or corporations receiving federal assistance, not merely the component of the entity that received the support. The regulations that fortify Title VI define discrimination as being either (a) acts that are intentionally discriminatory or (b) acts that are unintentionally discriminatory, but resulting in a discriminatory effect. A discriminatory effect is determined by a statistically significant *disparate* impact on a protected minority group. The operative word is *disparate* (or *disparity*).

Although Title VI applies very specifically to certain acts and institutional domains, the application has been transferred to how we evaluate the health status among minority groups. Borrowing directly from the legal language of Title VI, we have come to speak in terms of "disparities" when referring to the health of African Americans and other minorities. The Healthy People 2000 Objectives are replete with references to statistically disproportionate disparities between Blacks and Whites across numerous disease states, disorders and other public health conditions.

Set with the intent of being achievable, none of the national health objectives for minority groups have been set to surpass that of White Americans. Most national health objectives for minority groups were set somewhat between the baseline of the respective minority group and that of White Americans for the specific health condition. The aim of health promotion and disease prevention activities directed at African American and other minority groups is typically to lessen the health disparity by raising the health statistic associated with the minority group to closer approximate that of White Americans.

It is, indeed, important to establish a benchmark for what is considered an optimum goal for improved health status. And, it is certainly telling to contrast health status across groups to demonstrate differences that warrant explanation and intervention. However, it could be questioned whether or not Civil Rights statutes should serve as the template. Should the White population be the established norm or standard upon which minority health objectives are determined? In fact, objectives exist to improve the health status of the national population (which is skewed heavily in the direction of the White American population). Thus, with the theoretical achievement of health objectives of the White majority and the various minority populations, perpetuation cross-racial health disparities will continue to exist and is inherent to the design.

Another measure that follows the same Civil Rights template is the notion of excess deaths. Accordingly, excess deaths are determined to be the number of deaths from a specific cause that occurs within a specific minority group that proportionately exceeds the number of deaths in the White population due to the same cause. Here, again, the mortality rate of the White American populations becomes the "ideal" benchmark to determine success in lessening the discriminatory effect or the disparity in the respective minority groups. Again, the application of Civil Rights models to objectives for mortality is questionable.

What models should be used for determining optimum health and life expectancy? Well, in my scientific Utopia, health objectives would be species specific rather than race specific. The only race for which health objectives would be established would be the human race. All Americans would have the same objectives for optimum health and those objectives would be high for everyone.

In my scientific Utopia, the notion of excess deaths would not be based on cross-racial comparisons of mortality rates for various causes of death. Any death that is due to anything other than the natural progression of "old age" would be considered an excess death, regardless of race.

SOCIAL BARRIERS

Finally, I will describe one of the social barriers to multicultural research. The resistance to the conduct of multicultural research on a large scale is considered with the relatively low level of importance that minority health is deemed in this country. Even without cross-racial comparisons, by any standards, the morbidity and mortality rates for the leading diseases and health problems are outrageously high for African Americans. Stroke, hypertension, coronary heart disease, AIDS, cancer, diabetes, violence and other causes are killing African Americans at unprecedented rates. Countless thousands of African Americans die needlessly of preventable causes each year.

When other species are diminishing in numbers, various public and private agencies and societies rally to their rescue and the federal government can legally declare them as "endangered" which qualifies them for protection under federal laws. While I would never suggest that African Americans be declared an endangered species, it is appalling that there is no similar sense of outrage or urgency to address the extreme morbidity and mortality rates among African Americans. Tongue in cheek, a Trustee of the National Medical Association recently lamented that, in order to gain attention to the untenable health status of African Americans, we would first have to rob a 7-11 store.

What we need is a major national uprising for multicultural health science. Just as we have Mothers Against Drunk Driving (M.A.D.D.) and Mad Dads against violent crimes, we need an outcry of Mad Scientists who are enraged enough to take on the health of African Americans and other minorities as their life mission and their social, political and professional cause. Such researchers may wish to continue to distinguish basic science from social science and political science. But, make no mistake about it, basic science must be both social and political if it is to be responsible science. That would be Science with a capital "S." In fact, that would be SCIENCE in "*all* caps!"

Dr. Anderson, Dr. Holland and Dr. Snow—Howard University and NIDCD—I applaud you, salute you and congratulate you for taking this step to the alter. But, when the minister gets to the part that says, "Can anyone show just cause why these two should not be joined," there will be lots of rumblings for reasons I described this morning and more. And, if you end up joined in scientific matrimony, despite those rumblings (and I hope you do), you will be embarking upon a scientific revolution.

God speed to you as you begin this important journey together.

EPIDEMIOLOGY OF STROKE AND CEREBROVASCULAR DISEASE IN MINORITY POPULATIONS

Louis R. Caplan, M.D.

Stroke is by far the most common disease that causes language abnormalities in adults. Stroke is a very heterogeneous condition. The term stroke includes all acute brain dysfunction caused by abnormalities of the blood vessels that supply the brain with blood. Different stroke types (brain hemorrhage and brain ischemia) and even subtypes of ischemia (embolism, thrombosis, hypoperfusion) cause different brain lesions. Intracerebral hemorrhages are mostly due to hypertension and involve primarily the deep structures in the brain including the basal ganglia and thalamus. Hemorrhages usually do not include the major language regions in the cerebral cortex.

Within the large category called "thrombosis" (defined as occlusive arterial narrowing often with superimposed thrombosis) the brain lesions vary greatly depending on the site of the arterial occlusion. Patients with carotid artery disease in the neck have a different distribution of brain lesions than those patients with primary intracranial arterial disease involving the middle cerebral arteries. Carotid artery occlusive lesions usually cause intra-aterial embolism to cortical regions supplied by the superior and inferior divisions of the middle cerebral arteries, or involve cortical regions at the border zones between the middle and the anterior and posterior cerebral arteries. The superior division of the left middle cerebral artery supplies the cortex above the sylvian fissure including the left frontal and superior parietal lobes. Infarcts in this distribution usually cause a nonfluent Broca type aphasia accompanied by right-sided limb paralysis. The inferior division of the left middle cerebral artery supplies the temporal and inferior parietal lobes, structures mostly below the sylvian fissure. Lesions in this region usually cause fluent Wernicke type aphasia or conduction aphasias or a variety of auditory-related hearing and language deficits, and defects in reading, writing, and spelling. Patients with intrinsic middle cerebral artery disease usually have deep infarcts involving the basal ganglia and internal capsule or small wedge-shaped cortical infarcts. The infarcts in patients with intrinsic middle cerebral artery disease are smaller than those found in patients with cardiac-origin or carotid artery-origin embolism. The aphasias found in patients with basal ganglia infarcts are similar to those found in patients with small basal ganglia hemorrhages. Cardiac-origin embolism is a common cause of stroke and usually causes complete middle cerebral territory infarcts which on the left side would produce a global aphasia, or isolated superior or inferior division middle cerebral artery territory infarcts.

Patients with chronic hypertension have small lacunar in the basal ganglia and cerebral white matter and their cognitive and behavioral problems are different from patients with single acute large artery disease related infarcts. Lack of spontaneity, decreased amount and content of speech, and poor insight characterize those patients with extensive small artery cerebral disease. Speech repetition, speech comprehension and memory are usually relatively preserved. Understanding the type of vascular disease and the location of infarction and brain hemorrhage helps clinicians understand the nature of the cognitive and behavioral abnormalities and helps them predict the prognosis. Many studies show that white men have a different distribution of occlusive disease than women and African-Americans, blacks from South Africa, individuals of Chinese, Japanese, Thai, and Korean ancestry. White men tend to have severe occlusive lesions at the carotid artery bifurcation in the neck. They also have a high frequency of coexistent vertebral artery occlusive lesions in the neck, coronary artery, and peripheral vascular occlusive disease. Hypertension and increased blood lipids are also common. White men with carotid and vertebral artery disease in the neck, and those with coronary and peripheral vascular occlusive disease tend to have relatively low HDL cholesterol and high levels of LDL cholesterol.

In contrast, persons of Asian origin, blacks, and women tend to have more intracranial occlusive disease involving the middle, anterior, and posterior cerebral arteries and the intracranial vertebral arteries and their main branches. Coronary and peripheral vascular occlusive disease, and occlusive disease of the large renal arteries are less common than in white men. Hypertension is very common. Hypertensive intracerebral hemorrhage, lacunar infarcts, and chronic microvascular disease are also more common in blacks and Asians than in white men and women.

The distribution of occlusive vascular lesions found in African Americans, that is, a predominance of intracranial large artery occlusions and penetrating artery disease and a relative underrepresentation of extracranial occlusive disease, is also found in black patients in South Africa. In Asian populations, intracranial stenosis and occlusion are found in China, Hong Kong, Taiwan, and Boston's Chinatown.

In all of the populations studied especially African-Americans and Asians there is a recent trend for more frequent development of the same pattern of occlusive disease traditionally found in while males, that is, occlusive extracranial, coronary, and peripheral vascular disease. In studies of Japanese-origin patients in Japan, Hawaii, and California, those in Japan had primarily intracranial occlusive disease and a low frequency of coronary artery disease, while patients from the same region of Japan who had emigrated to California had relatively more extracranial and coronary artery disease. Those Japanese from the same region who emigrated to Hawaii had frequencies of disease intermediate between the Japanese and California groups. These studies show that environmental factors (possible diet, stress, or other uncertain factors) can change the usual genetic pattern of atherosclerotic disease.

There have been very few pathological studies using modern techniques comparing qualitatively and quantitatively intracranial lesions according to race and sex. It is possible that the intracranial stenotic lesions in blacks and Asians are different from those customarily found in whites. In blacks and Asians there may be more involvement of the vascular media with smooth muscle and collagen overgrowth. White men tend to have more intimal and subintimal fatty, atherosclerotic plaques. These posited morphological differences could explain some of the differences in the clinical findings. White men with middle cerebral artery stenosis tend to have more TIAs and more responsiveness to coumadin treatment than blacks and Asians. Blacks and Asians often have strokes rather than TIAs and do not respond as well to coumadin. Their strokes may be due to decreased blood flow due to vascular obstruction. Intimal plaques might be more associated with small emboli which could cause TIAs and be prevented by coumadin or aspirin prophylaxis.

Clearly more studies of the pathology of the intracranial arteries are needed using modern technology for evaluating the content and nature of plaques and the constitution of the vascular intima and media.

There have been a number of different explanations posited for the racial and sex differences. The racial groups with a high frequency of intracranial occlusive lesions-black and Asians, also have a high frequency of hypertension. Researchers have most often posited that hypertension causes the intracranial disease. However, when series of patients with strokes have been analyzed, white male hypertensives do not have the same distribution of vascular occlusive disease as those found in blacks and Asians. Differences in diet, sodium intake, blood lipids, and coagulation factors have also been mentioned as possible causes.

Hypertension can be of the high-resistance or high-volume types. Blacks and Asians tend to have more high-volume hypertension. Other conditions such as pregnancy and the puerperium and use of full-strength oral contraceptive pills, and diabetes mellitus are conditions which are also characterized by increased blood volumes, and are associated with intracranial vascular occlusive disease. White men tend to have more high resistance hypertension. High volume states may predispose to intracranial occlusive disease while high resistance hypertension is more often associated with extracranial cerebrovascular, peripheral vascular, and coronary artery occlusive disease.

PSYCHOSOCIAL SEQUELAE OF STROKE INDUCED COMMUNICATION DISORDERS (SICD) IN A MULTICULTURAL POPULATION

Martha Taylor Sarno, M.A., M.D. (Honorary)

Dr. Snow, Dr. Ruffin, and Dr. Anderson, it is both a pleasure and privilege to be a part of this very important conference. I come with the hope that this is only the beginning of an initiative which will make a difference in the care of individuals with stroke induced communication disorders in minority populations.

When one considers the voluminous literature concerned with the broad spectrum of communication disorders it is surprising to note the sparsity of attention to their psychosocial sequelae. The geometric increase in the communication disorder literature, especially since World War II, does not include a proportionate increase in studies devoted to psychosocial matters. Head (1925) in his two volume treatise on aphasia, and Weisenberg and McBride (1935) in their 600 page volume Aphasia, made almost no reference to psychosocial factors, except for an allusion to the influence of premorbid personality, and I quote, "the patient who has weathered many storms cheerfully ... either feels confident that he will improve and is encouraged by slight progress, or he adjusts himself quietly to conditions as they are" (p. 428). Later, others, such as Joseph Wepman (1951) and Jon Eisenson (1949, 1973) said a great deal about the psychological sequelae of aphasia, even going so far as to recommend psychotherapy. From the forties through the early sixties a number of clinicians included psychosocial sequelae as an important part of their observations; (Backus, 1947; 1952; Nielsen, 1948; Corbin, 1951; Blackman and Tureen, 1950; Schuell et al, 1964). However, many of these observations were derived primarily from patients with head trauma and, as a result, could not be generalized to the poststroke aphasic population.

The speech code is unique to the human species. Human communication encompasses many levels of activity ranging from the delicate, rapid sequences of sensory and motor events necessary to produce the acoustic features of the speech sound stream to the subtle shades of meaning that occur in the cognitive/semantic spheres. Gestures, pantomime, pragmatic behaviors, such as turn taking, all contribute in significant ways to this highly interactive human behavior. Social interaction, essential to the establishment and maintenance of relationships, requires communication (Wahrborg, 1991). As a consequence, human communication is closely related to personhood—that composite profile of the individual's 'self', personality, attitudes, lifestyle, experience, judgment, self determination, temperament, level of initiative, humility, ego, religious traditions, beliefs, achievement level and every other feature and factor that characterizes each of us as individuals.

The sudden and unexpected occurrence of a stroke induced communication disorder (SICD) (hereafter to be referred to as SICD), strikes at the very core of the person. Its inevitable negative impact on one's identity and self perception, has lead some authors to characterize the psychosocial sequelae of SICD as central, not secondary, to the problem (Code and Mueller 1991, Sarno 1986, 1993).

Clinicians are aware that the very important impact of psychological and social sequelae in the population of individuals with SICD often persists well beyond the termination of rehabilitation, independent of the severity of the disorder or associated physical dysfunction, and these sequelae may represent the most significant deterrents to an acceptable quality of life (Feibel and Springer 1982; Labi et al 1980; Robinson and Price 1982). Further, the magnitude of psychosocial consequences may have little relationship to the type or degree of communication impairment or disability.

The tendency to conceptualize SICD as only linguistic or motor speech impairments, a cerebro-pathological state rather than a catastrophic life event, makes it unlikely that the psychosocial dimensions of the condition are considered in the clinical or research environment.

As I prepared these comments, it became clear that because of the limited information on the topic a focus on stroke induced communication disorders in our diverse population would first require a review of what has been said about the psychosocial sequelae of these disorders and some clinical observation.

Let us now briefly review what has been said about the psychosocial consequences of the most common categories of SICD: the aphasia syndromes, verbal apraxia, the dysarthrias. and the communication deficits associated with right hemisphere pathology. It is understood that each diagnostic category contains subcategories with their characteristic manifestations in communication behavior of each of these may range in severity from "barely perceptible" or mild to severe.

The Aphasia Syndromes

Greater attention has been given to the psychosocial sequelae of the aphasia syndromes than all of the other SICD. Yet, our level of knowledge, beyond clinical observation and personal accounts, remains limited and inadequate. Few studies have specifically addressed the psychosocial aspects of patients with poststroke aphasia.

Although non-aphasic observers would concur with Code and Muller that people with aphasia must "negotiate a new understanding of their worlds and others in it" (1989) one can only speculate and never really know how it feels to be altered in one's interactive life. A great deterrent to our understanding in this area is the fact that aphasia renders the individual impaired in his ability to communicate the details of the experience (Herrmann,1989). Jaffe, a psychiatrist and aphasiologist, pointed out that patients with aphasia are subject to the full range of psychiatric disorders seen in the general population, but, because of the communication disorder, the psychological sequelae may not, in some instances, be recognized until the patient manifests symptoms of a psychiatric disturbance. He also stated, "A good clinician understands that an acquired aphasia is probably the worst disaster that has ever occurred in the patient's life" and "human beings can adapt themselves to almost any situation if they can communicate with others about it." (Jaffe, 1981)

From a clinical observation perspective one has the impression that there are distinctly different sequelae in nonfluent aphasia and fluent aphasia of the Wernicke type. The high level of awareness and relatively intact auditory comprehension generally present in nonfluent aphasia seem to produce predictable reactions to the condition. The person with fluent aphasia, on the other hand, may manifest signs of bizarre desperation, as (s)he tries to make sense of the speaking world. A lack of awareness combined with impaired auditory comprehension are a formula for a frantic, impulsive, reaction to the feeling of losing control over ones interactions.

The best studied psychological sequela of aphasia is depression which is said to occur in 60-70 percent of this population (Mapelli et al 1980; Sarno 1993; Horenstein, 1970; Warborg 1991). Some report depression as long lasting (Robinson and Price 1982; Lendrem, 1988). In a recent study, subjects three to five years poststroke showed higher levels of depression than those who were less than two years post onset (Penn 1996).

Depression in poststroke aphasia has been interpreted both as a reaction to the consequences of the stroke, a "grief response" and as a "catastrophic reaction," a type of physiologic affective reaction to brain damage. Studies which have correlated laterality of brain lesion with emotional behavior report that patients with left hemisphere lesions and aphasia manifest catastrophic and anxiety-depressive symptoms more often than right hemisphere damaged patients. The latter tend to appear unaware and indifferent to their deficits (Gainotti, 1972). Herrmann related depression in aphasia to the course of recovery. In each stage of recovery and rehabilitation the aphasic patient is said to have a specific vulnerability for the development of mood disorders. Some believe, that in the first stage, up to two months poststroke, the depression is caused by direct structural and biochemical consequences of stroke; in the second stage, two to six months poststroke, psychoreactive mood changes are the result of the individual's realization that the condition may be permanent; in the third stage depression may result from an awareness of the scope of family, professional and social alterations produced by lasting impairment (Herrmann, 1991; Warborg, 1991; Kubler-Ross, 1969).

Personal accounts of the experience of living with aphasia have confirmed the prevalence of depression, feelings of hopelessness and helplessness (Wirt, 1967; Wulf, 1973; Moss, 1976; Segre, 1976; Newborn, 1997).

Documented comments from persons with aphasia highlight the anxious and depressed quality of their reactions. I quote: "You're afraid of human contact. That awful feeling of being a prisoner within myself. I had to tolerate constant interruptions. My aphasia involved my whole social and emotional being (Newborn, 1997). For over three months, I was in a bleak, gray-black desert, barren, no sound, no color ... everything was dead. I was on an island; a stranger, afraid, in a world I never made."

When Craig Robertson, a 37-year-old right hemiplegic person with aphasia, testified before an expert panel on post stroke rehabilitation of the Agency for Health Care Policy and Research (AHCPR), he said: "The biggest problems for me after the stroke were not the physical but the stroke's impact on me and my family, on me and my friends on me and my job ... it struck all of us and I'm still recoiling ... stroke actually is a lifelong recoiling, not a couple of weeks, or months, or years ... a lifetime of recoiling with my family, friends, and coworkers. ... The emotional and psychological toll stroke takes on me and my family is even more devastating than the financial toll. The fear, the anxiety, the anger ... all weigh heavily."

Roger Ross testified: "I assumed my speech would return fully with the work with a speech therapist ... I gradually started to feel that my speech might never return to normal nor my reading nor ability to write. I became extremely depressed and for many months even contemplated suicide. ... I do not know how I could have survived this period without the concern of all the people who helped me not only to speak but to think positively about the future. ... People like me who have aphasia clearly need psychological help along with the other therapies. Most stroke patients I have spoken to agree with me on this."

The "grief response" model of depression after stroke is remarkably similar to the model of loss identified in the psychology of disability where acquired disabilities are considered losses (e.g., of self, identity, inability to continue personal contacts, family and social roles, income). People with aphasia may also experience symbolic loss in the form of altered perceptions of their familial, social, and vocational roles. The grief response generally begins with a period of denial in which the person expects to make full recovery, followed by a period of awareness that the stroke sequelae may be irreversible. A period of mourning is generally believed to be a necessary process if adjustment to aphasia is to occur (Brumfitt and Clarke, 1991). The reactive experience of awareness of loss is complex, produces grief, and involves many emotions and attempts to adjust and cope with loss.

Denial is common in the person with aphasia and may take the form of an indifferent affect, chronic fatigue, and unrealistic expectations for complete recovery (Sarno, J., 1991). In her now classic model of the stages intended to characterize the adjustment to death and dying, Elizabeth Kubler Ross (1969) identified the first stage in the grief process as one of denial. It has been pointed out that denial may be a means of borrowing time while adjusting to reality in an altered state (Baretz and Stephenson 1976). It may be an attempt to resurrect the past, and avoid being confronted by an awareness that might be overwhelming, or too painful (LeTourneau 1993).

Persons with aphasia and their families are acutely aware of being socially isolated. Friends gradually drift away from their circle and even family members may withdraw. In a national survey conducted by the National Aphasia Association (NAA), 88 percent of the 536 respondents indicated that social isolation was the primary problem resulting from their aphasia, and 70 percent believed that people avoided them because of their communication difficulties (NAA, 1988). In handwritten comments which patients and their families included in the questionnaire responses frequent mention was made of loneliness, difficulty making friends, lowered self esteem, depression, hopelessness, and despair.

Last week, the NAA contacted the leaders of 170 Aphasia Community Groups by telephone in a survey designed to prioritize topics for the first national Aphasia Community Group Conference, which will be held next year. Twenty-six groups representing 15 states responded. The most common themes mentioned in order of frequency, were: coping with depression; coping with frustration; coping with anger; emotional needs of caregivers; and identifying and accepting changes in relationships. The results were consistent with the survey findings ten years earlier.

Recently, the team at the York-Durham Aphasia Centre in Ontario, Canada, assessed the effectiveness of a community program on various psychosocial variables in poststroke aphasia participants in their program and the motivation of their significant others. Two parallel rating instruments were used: How I see Myself and How I see My Aphasic Spouse/Family Member. The results indicated that by providing structured opportunities for dialogue, communication partnerships with volunteers and professionals, decision making, and participation in community life, the program had a significant effect on psychological well-being. Furthermore, there was a noticeable reduction in stress-related health problems and the need for health and social services. (Thelander et al, 1994; Patterson and Wells, 1996)

In some patients a fear of rejection by family and friends is sufficient to create an environment that leads to social isolation (LeTourneau, 1993). Aphasia may rob the individual of the solace through human contact usually available to people who have suffered a devastating loss by being able to talk about it ... a kind of healing conversation (Jaffee, 1981).

Premorbid Personality

The influence of premorbid personality on living with aphasia is often invoked in personal accounts as well as clinical observations. Moss, a psychologist who wrote a book about his experience with aphasia, stressed the influence of his premorbid personality indicating that he used the same compensatory behavior patterns after the stroke as before (Moss, 1976). I recall an elderly gentleman, who was both wheelchair bound and aphasic, who clearly felt himself to be in command of himself and those around him. His indomitable will was readily apparent, reminiscent of Henty's famous poem, *Invictus*:

"In the fell clutch of circumstance, I have not winced nor cried aloud. Under the bludgeonings of chance, my head is bloody but unbowed."

This may be somewhat dramatic--but it makes the point.

Those of us experienced in managing patients with neurogenic communication disorders can relate examples of extraordinary individuals with SICD whose strong sense of self and inner strengths have facilitated the resumption of a relatively normal life. The drive to redefine oneself, while rare, does happen.

A good example is Joseph Chaikin, the playwright-actor-director, who has lived with severe aphasia for almost ten years and has continued to function successfully in all of these roles. He writes, produces, directs and acts all over the world in spite of a severely reduced access to expressive language for as well as some auditory comprehension impairment. Chaikin writes poetry about living a "new life," one with different meaning and values, and about the meaning of words and communicating with his public through the theatre. He refers to himself as a new person; someone who has recreated himself in a new image. The experience of a catastrophic life event can bring inner resources to bear on one's reflections about the purpose of life and ones values, which may lead to a "redefinition" of oneself.

There is still only sparse data available regarding the longterm psychological and social evolution of patients with aphasia secondary to stroke. Clearly, a person's values play an important role at all stages of recovery and reintegration into the community. What is a disability and/or a handicap for one person may not be for another.

Family life after the onset of aphasia is profoundly altered in all respects. The free flowing exchange of speech so typical in the family setting may be awkward, marked by frustration and errors of information. Aphasia has been described as a disruption in normal family life (Wahrborg, 1988) and as devastating for the entire family (Sarno, 1970, 1981; Williams and Freer, 1986). Its unpredictable course and inevitable impact on a family's sources of gratification represents a major shift in the family life cycle. Stroke families, whose constellation includes a person with a communication disorder, may perceive their poststroke existence as an evolving series of time segments of varying lengths. The acute illness, which comprises the first time segment, is followed by a period of awareness of the chronicity of the condition and the spectre of disability. If the person is able to make an adjustment to his/her altered state, community reintegration becomes an achievable goal. Time, in terms of expectations for recovery and adjustment, time of life, and stage of recovery, become the focus of the family unit as it evolves and adopts new life strategies for adaptation to new roles.

In recent years, caregivers have become a focus of attention as society begins to move toward returning the long-term care of the chronically ill and disabled to families and the home. The assumption is that families are best able to manage such care and have the moral, psychologic, and spiritual strength to do so. Callahan (1988) suggests that we need "improved systems of social support for those who care for family members ... the financial and psychologic support of state and federal agencies, and ... responsive, sensitive people to give them help and ... respite." He also points out the inevitability of feelings of anger and subsequent guilt in the majority of caregivers of chronically ill/disabled family members. These feelings, as well as isolation and rage, are frequently confirmed by caregivers in personal accounts (Bendetson, Jane, *NY Times Magazine*, April 13, 1997).

Callahan says further, "We need a different kind of society. One that recognizes that our out-of-harmony health care system has led us to spend too much on health care in comparison with other social needs ... too much on the acutely ill in comparison with the chronically ill, too much on curing in comparison with caring, too much on expensive individual health needs, and too much on extending the length of life rather than enhancing the quality of life." (Callahan, 1996)

In one study, spouses of aphasic patients showed evidence of significantly poorer overall social adjustment when compared to spouses of nonaphasic stroke patients (Kinsella and Duffy 1979), and it appeared that problems of readjustment frequently worsened with time. High levels of depression have been reported in the caregivers of communication impaired patients, although men generally report less depression than women (Kinsella and Duffy 1979; King, Shade-Zeldow, 1995).

Marital communication is reported as a severe problem more often in aphasic than non aphasic stroke patients (Artes and Hoops 1976; Kinsella and Duffy 1979). Family members often have difficulty interpreting the altered responses of their aphasic relatives, suggesting that unresolved family conflicts may resurface during this adjustment period. Aphasia may impair a family's shared social and leisure life often isolating it from its social circle. (Jaffe, 1981; Kinsella and Duffy 1979; Friedland and McColl, 1987). Agreements about roles and responsibilities in the family may no longer apply. Not only may role changes occur, but the family may be strained if the person with aphasia controlled the family's social life, finances, or was in other ways the dominant family member. A high frequency of depressive symptoms has been reported in the spouses of stroke patients (Kinsella and Duffy 1978, 1979; Webster and Newhoff 1981) sometimes lasting for several years (Coughlan and Humphrey 1982; Holbrook, 1982).

Dysarthria

I have been unable to find reference in the literature to the psychological and social sequelae of dysarthria. Yet, the physical and acoustic characteristics of motor speech disorders have been studied extensively. How does one explain this neglect? Clinicians are acutely aware that individuals with dysarthria experience loss, lowered self esteem, isolation, depression and difficulties in community and vocational reintegration.

I am reminded of an African American gentleman with a relatively mild dysarthria who was so devastated by his altered speech that he was unable to return to work as a security guard in an art museum. His changed "speech identity" made a "redefinition" of self impossible.

Though the literature is silent about the psychosocial impact of dysarthria, experienced clinicians are familiar with the day-to-day social problems they encounter. The uncontrolled character of much dysarthric speech draws attention to itself in public places, bringing great discomfort both to speaker and listener. Persons with dysarthria may shock their listeners because of unexpected loudness, explosiveness, or sudden pitch change. Some may sound bizarre, or be thought to be intoxicated or on drugs. If the dysarthria is sufficiently severe, so as to render the person unintelligible, the necessity for repetition in order to be understood increases social awkwardness. Individuals with dysarthric speech may feel very different, and differentness, even in our diverse society, promotes feelings of discomfort and inadequacy.

This is a matter of current concern in my own department located in a rehabilitation center where the number of patients with dysarthria has increased considerably in recent years. Patients with dysarthria account for 40 percent of the current caseload, perhaps reflecting the fact that older, sicker patients are being referred for rehabilitation services and that dysarthria in this population may result from multiple factors, including reduced levels of energy and effort, cognitive deficits, and associated medical disorders.

Group therapy is often of great value to these patients, which provide both peer support from others with the same problem and a secure speaking environment. For some, it is one of the few settings in which they can derive some fulfillment from conversational interaction.

With regard to verbal apraxia, I have not encountered any mention of psychosocial consequences in the literature specifically associated with this disorder. Since verbal apraxia manifests itself in symptoms which may be similar to either dysarthria, aphasia, or both, all of the psychosocial sequelae already mentioned may be observed in this group. Clinical observations over the years suggests that this group of communication impaired persons may experience great frustration in communicative interactions as a result of the unpredictable nature of their speech output and their degree of awareness combined with reduced fluency. The psychosocial sequelae of verbal apraxia and dysarthria need systematic study to identify and compare their characteristics with those of the other stroke induced communication disorders.

Communication Disorders Associated with Right Hemisphere Damage

Literature which addresses the psychosocial sequelae of the right hemisphere damaged (RHD) patient is also extremely limited. One study reports that though these patients are aware of emotional content they seem unable to recognize the appropriate place or role of emotions in real life settings and situations (Cicone, Wapner and Gardner 1980).

Another study reported that some RHD patients have problems appreciating the visuospatial and acoustic/prosodic stimuli in which emotional messages are embedded which can lead to emotional misinterpretation (Blonder, Bowers, and Heilman 1991).

Data on galvanic skin responses, respiration, and heart rate indicate that some RHD patients are hypoaroused by emotional stimuli though they retain the ability to recognize them accurately, suggesting that autonomic and cognitive aspects of emotional processing can be selectively impaired (Zoccolotti, Scabini and Violani 1982; Heilman, Watson and Valenstein, 1986).

Speech-language pathologist clinicians are struck by the lack of affect and lack of correspondence between the content of what some RHD patients say and the prosodic and pragmatic skills they use. A joyful statement can be represented by flat, indifferent prosody and vice versa. The lack of a good match can be upsetting to friends and families. They may say "doesn't he really care?" The indifference displayed by many RHD patients can be disconcerting and upsetting to friends and families.

Psychosocial Sequelae of Aphasia in A Multicultural Population

Identifying, assessing, and managing the psychological and social sequelae of SICD in people of diverse cultures and ethnicity requires highly specialized skills and cultural sophistication. Although language assessment in various cultural groups was revolutionized in the sixties and seventies, especially for school age African Americans, assessment instruments based on standards derived from mainstream speakers continue to be in use for the evaluation of speech and language pathology regardless of cultural or ethnic background. This practice is especially unacceptable when it comes to the interpretation of discourse and pragmatic data where each cultural/language/regional group has its own unique code of meanings.

Culturally valid testing designed for individuals from the major minority groups who are at risk for SICD are nonexistent. Hence, clinicians and researchers who manage people from diverse cultures are handicapped due to insufficient familiarity and a lack of knowledge as to whether a given communication behavior is, or is not, pathological. This factor constitutes one of the major deterrents to a proper understanding and competence as to the nature of communication disorders in nonmainstream speakers since cultural factors define what is considered pathological (Taylor, 1986). For example, as Taylor and Peters-Johnson, 1986 point out, many normal African Americans without brain injury would be considered aphasic if a diagnosis depended on the results of existing aphasia tests. The same holds true in identifying or making judgements about a patient's emotional response to a communication disorder in the absence of a high degree of knowledge of the culture in which the patient lives and/or has lived. (Wallace 1996; Payne-Johnson 1992; Taylor 1986). Stroke induced communication disorders can only be defined from the perspective of the community of which a given speaker is a member (Taylor, 1986).

The features of human communication within cultural groups are closely related to the underlying history, traditions, values, and perspectives of each group. All of the world's languages have dialects which are unique to subgroups. Wolfram (1986) designated social status, regional features, ethnicity, gender and age related differences, and formal and informal styles as the major language variables affecting dialect variation. Cultural rules drive language behavior within groups and lend the communication behavior of a group its particular pattern and texture.

The point has been amply stated that language has an intimate relationship to culture and is acquired in a cultural context. In all groups, it is the most important means through which the culture is communicated (Peters-Johnson, 1986).

The following briefly reviews some salient ethnic and cultural characteristics of African Americans; Hispanic Americans; and Asian Americans.

Clearly, at this time, in the absence of data one can only infer how ethnic and cultural characteristics might influence the assessment and treatment of patients with SICD.

African Americans

African Americans comprise a heterogeneous community with great diversity of socioeconomic class, religious tradition, educational background, skin color, political persuasion and social belief. African Americans in the United States are, for the most part, descended or migrated from the Caribbean or directly descended from African slaves. Payne (1986) has indicated that differences in values, traditions, foods and language characteristics have been noted between the two groups. Superimposed on these differences are socioeconomic and educational differences among urban, rural, working class, and middle class African Americans. In the African American population there is strong evidence of the relationship of language to culture where the vernacular is intimately associated with the culture and serves as a cultural unifying device.

Communication disorders resulting from organic causes are known to exist across all of the world's cultures yet no figures are available regarding the worldwide incidence of SICD. However, since the incidence of stroke in the African American population in the United States is considerably higher than for whites, we can deduce that the incidence of SICD is also disproportionately higher than for whites (Holland, 1983). Despite the probability of a high SICD incidence, studies of aphasia in samples of African American subjects have been rare (Payne, 1986).

Judgments of pathology must be made from the vantage point of the indigenous or preferred system of communication of the person being assessed (Taylor, 1986). Misinterpretations of communication behavior, culturally inappropriate settings, negative attitudes on the part of clinicians, and the absence of culturally valid measures have contributed to the failure of existing diagnostic methods to identify speech and language pathology in African Americans. Peters-Johnson and Taylor, for example, describe how the insensitivity of existing tests of aphasia to the differentiation of aphasic-like responses from responses that might reflect normal language variations in many African American speakers might cause many perfectly normal people to appear aphasic! (Taylor and Peters-Johnson, 1986)

A study conducted by Marcus-Bernstein (1986) at Harlem Hospital in New York City focussed on the influence of ethnicity and culturally derived psychosocial factors on the functional severity of hearing loss. The interaction of hearing handicap and nonaudiologic factors, such as coexisting physical and psychosocial factors, in 100 elderly African American patients comprised the basis of their findings. The study showed a relationship between perceived severity of loss and decreased social function. The African American subjects in this study experienced less life satisfaction and were limited in either social support, economic resources, mental functioning (depression), health and/or activities of daily living. These results provide further evidence that the special needs of African Americans are underrepresented in the literature. While the findings do not bear directly on the SICD population, inferences can be made by analogy.

Payne-Johnson (1992) identifies four areas of primary importance in the study of elderly African Americans and communication disorders: religiosity, relationships to family and fictive kin, leisure activities and educational interests. In the case of religiosity, elderly African Americans, are generally more involved and more vigorous in formal religious activity than their white peers. The church represents a significant component of daily social, supportive, and spiritual life. Although inner city African Americans have been found to have fewer financial resources and are more likely to live alone, they receive greater support, have frequent contact with relatives, and are more likely than their white peers to have their needs met by these relatives. Strong kinship bonds, an underlying resourcefulness, and flexible family roles have been cited as contributing greatly to the survival of African American families allowing them to cope with and transcend some of the barriers to meeting their economic and psychic needs (Hill, 1972; Johnson and Barer, 1990).

The African American family is a strong unit that relies on a kinship network where its elderly members are supported by collective efforts within and outside of the family. Households often have "elastic boundaries" where everyone in the kinship operates in and out of the kinship home. In times of crisis, the flexible family roles act as a strength. In some families a three generational system can be in operation where the grandmother plays a central role. Although females identify mostly with their roles as mothers and both males and females maintain flexible roles when it comes to child rearing issues, males demand recognition as head of household. It is not uncommon for African Americans to believe that hard work does not bring rewards. Further, they have the expectation that troubles are inevitable—a result, perhaps of a history of oppression. Based on negative experiences African Americans sometimes believe that health professionals are of questionable value. Because of a strong religious or spiritual orientation. They may tolerate difficulties without the inclination to explore and understand their condition. Furthermore, some view emotional difficulties as the "wages of sin," feeling that their emotional difficulties reflect a failure to believe and practice biblical principles. (Hines and Boyd-Franklin, 1982)

African Americans have a great sense of respect for the elderly and tend to care for them at home rather than placing them in nursing facilities. For some aging African Americans leisure time is perceived as any nonobligatory activity and topics of interest are not necessarily those of interest to their white peers. These factors could easily be misinterpreted in the SICD patient in the determination, for example, of functional communication goals. These kinds of observations point to the need for formal studies to identify the impact of the specific ethnic, cultural and psychological factors that characterize the African American community and their interaction with stroke induced communication disorders.

Hispanic Americans

Currently, Hispanics are the fastest growing minority group in the nation. The Hispanic population which is estimated to number about 15 million individuals, includes a broad representation of cultures bound together by one language. In the United States the major Hispanic populations are Puerto Ricans, Mexican Americans, and a much smaller population of Cuban Americans who immigrated to the United States in 1959 as a result of the Castro revolution.

The influence of a long standing history of Spanish rule is widely evident in all of the Hispanic groups. Spaniards brought not only their language but literature, foods, and Roman Catholic religious rituals for birth, marriage and death, a patriarchal family structure, and a strong sense of family obligation.

Puerto Ricans reflect a mixed racial heritage of Indian, African and Spanish ancestry. They have migrated to the United States in large numbers, especially in the Northeast. Mexicans, the second largest Hispanic group in the United States, are generally from rural villages. The have settled largely in California, Texas, and the Southwest and continue to cross the border, preferring economic exploitation in the U.S. to the poverty conditions in Mexico.

In both the Mexican and Puerto Rican cultures, the nuclear family is embedded in an extended family network. Orphans or children of divorced adults, widows or divorced single adults may be included in the households of relatives. Nuclear families preserve their identity by living nearby but separate from the extended family. Great value is placed on the family, both immediate and extended, as well as close friends.

Despite a shared language there are distinct cultural differences among Spanish speaking groups in the Americas and Spain, though one may find many similarities in religion, philosophy of life, family structure and gender roles.

The migration of Puerto Rican families to the United States mainland and the development of Puerto Rican communities, particularly in the Northeast, has continually expanded, although there is an ongoing back and forth movement between the island and the mainland that has had a strong influence on Puerto Rican family life (Preto, 1982) Puerto Ricans present different styles of communication depending on their origins. In poor rural families individuals tend to be soft spoken and have a less verbal, slower pace than urban middle class families. Persons in the middle and upper classes value possessions as highly symbolic of personal worth whereas the lower classes emphasize spiritual and human rather than commercial value. Puerto Ricans live for the present, the future and past are not given much attention. They are as a group, nominally Roman Catholic. A large number believe in spiritism ... that is, that spirits can either protect or harm as well as prevent or cause illness. Every person is seen as having spirits of protection. Puerto Ricans value the family's unity, welfare and honor. Family ties and relationships are intense and visits are frequent. The family is patriarchal and the husband is free to make decisions without consulting his wife. His major responsibility is to protect and provide for his family and he is expected to be hardworking and macho.

Puerto Ricans tend to attribute stressful situations to external factors and to express their stress through somatic complaints. If a problem is perceived as nonphysical then it may be thought to be spiritual. A disproportionately large number of Puerto Ricans in the United States live below the poverty level (approximately 38 percent). Racism can also affect a Puerto Rican's economic situation.

With regard to stroke survivors, the conflict that may arise in a Puerto Rican marriage may be considerable if roles are reversed and the woman must obtain employment while her husband takes care of children. Husbands are likely to feel emasculated under such circumstances.

The Mexican-American in the United States population is estimated at well over 6.5 million. The 1970 census figures show that most Mexican Americans living in the U.S. were either born in Mexico or born to Mexican born parents. There are, however, Mexicans who have lived in the southwest for several generations. The majority of Mexican Americans are a mix of Spanish and Indian descent tracing their ancestry back to Indian culture which built great civilizations in Mexico long before the Spanish explorers arrived. Their predominant religion is Roman Catholic. (Falicov, 1982)

Machismo dictates that men be aggressive, strong, brave and protective of women and children. Females are humble, submissive and virtuous, devoted to home and children.

Their emotional problems are often the result of social interactions between nuclear or extended family members. Some Mexican families turn to rural folk medicine in the event of illness or disability but the majority turn to the church in the form of promise making, offering, prayer offering and votive promises that usually include deprivation of some physical comfort.

Hispanics are generally fatalistic in their views of illness and disability which are generally perceived as acts of God. Frightening experiences, such as the death of a loved one or witnessing a frightful event, are sometimes believed to cause an illness such as stroke. Hispanics often do not seek medical care, viewing pain, illness, and disability as a natural and necessary part of life (Miller, 1997). Some turn to the church in the face of disaster, through prayer or offerings while others turn to sorcery, witchcraft, or ancient herbal lore, practices that are common in Mexican culture. (Falicov, 1982).

The Asian-American Culture

The Asian American population in the United States is comprised of people from China, Japan, the Philippines, Burma, Vietnam, Laos, Malaysia, Cambodia and Thailand. While these groups do share many aspects of social structure, particularly in the family unit, they are different from each other in more than just language. As is true of all minority populations, socioeconomic, generational, gender and educational factors account for different subgroups. Differences are particularly salient between the elderly, less educated, sometimes illiterate, generation and their children who may be totally assimilated into mainstream America.

For the most part, Confucianism and Buddhism prevail in the traditions of the Asian cultures. These systems do not stress autonomy and independence but rather that the individual is superseded by the family. In the Confucianist tradition there are specific hierarchical roles established within the family and the rules of conduct are more formal than in most other cultures.

Males have unquestioned authority in the Asian tradition and the influence of the mother/wife is more covert as opposed to the overt authority of males. Males feel especially stressed and anxious after a stroke and many tend to deny the existence of psychological problems related or unrelated to the stroke. Mothers are nurturant, emotionally devoted and submissive. Along with male authority is responsibility and in the eyes of the community the success or failure of the family as a unit is attributed to the father.

Highly developed feelings of obligation govern much of the traditional life of people from Asian cultures. Shame and loss of face are frequently used to enforce adherence to obligations. The greatest obligation in the Asian family is to parents.

Unlike Western cultures that emphasize the single nuclear family with a time-limited life span, the extended Asian family is not time limited. It extends both forward and backward. As a result, an individuals actions reflect on all preceding generations and impact on all future generations.

A crucial function of the family structure is to provide a framework of mutual independence, so that family members rely on each other for support. For example, "Chinese American socialization involves the development of strong affective bonds between family members. These bonds are continually emphasized such that an individual's self-esteem and future become significantly bound up with the family and kin"... Emigres to the United States lose the extended family network; relatives and close friends are often no longer available to provide support (Son and Ja, 1982).

An advantage of the extended family network in the event of a stroke is the potential for less pressure on a patient's partner than occurs in the typical western nuclear family. On the other hand, the interdependence of individuals within the extended family can create problems when an important member of the family becomes disabled such as may occur with SICD. The disability may put the family at risk since traditional roles within the family structure are considered crucial to the integrity of the family constellation.

Asian families generally perceive stroke differently from American families. Many see the occurrence of a stroke as a result of their ancestor's wrongdoings or fate. As a consequence, they may feel more ashamed or embarrassed than their American counterparts. Talking about their disabilities or feelings is perceived as a sign of weakness or an imposition on the listener. This attitude tends to make Asian Americans less communicative/expressive than the Western patient after stroke. As a result, the possibility exists that the features of a SICD may be difficult to identify.

The communication style of Asian American individuals is dictated by age, gender, education and other factors which may pose problems to the health professional interested in discovering information about family life, prior history, and feelings. The communication style is not open, affection is not expressed openly, disagreement and confrontation are avoided.

Some Asian Americans view Western rehabilitation practices as so different from Eastern intervention (e.g. herbal medicine, acupuncture) that they may be reluctant to receive services resulting in poor attendance and motivation.

Conclusion

Clinical experience and the feelings expressed by those with stroke induced communication disorders and their families reveal that the magnitude of distress they experience is considerable.

When psychosocial sequelae interact with ethnic-cultural factors in the minority populations, there is little basis for recognizing and understanding them. Not only do we lack culturally valid assessment tools but there is virtually no data from systematic studies which can inform us about their incidence and impact in the major nonmainstream populations and their subgroups.

These issues are multifaceted and complex. They require thoughtful, creative methodology and committed specialists to seek solutions. Hopefully this conference will make this possible. The rapidly expanding diverse character of our nation lends urgency and high priority status to this compelling challenge.

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CULTURAL VARIABLES IMPACTING ON STROKE AND ITS SEQUELAE

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I am extremely delighted to address this historic and important conference on cultural variables as these relate to stroke and stroke sequelae. In 25 years of graduate college teaching in speech-language pathology, I have found our research and instructional materials to be woefully lacking in depth and scope on African Americans and stroke. Except to note that African Americans are more at risk for strokes and aphasia than whites and that urban blacks are infrequent participants in clinical services for aphasia, the existing research has been extremely limited to date. This conference affords the first opportunity to bring researchers and educators together to explore stroke and its sequelae within the cultural context. My presentation focuses on African Americans as they are considered to be the fastest growing group of older ethnic adults and the group most at risk for strokes and disabilities.

It is crucial to understand the cultural dynamics of African American mature adults because of radical shifts in the demography of African Americans and other persons of color in the 21st century. Stroke risks double every decade after age 55 (Dyken, Wolf, Barnett, Bergan, Hass, Kannel, Kuller, Kurtzke, and Sundt, 1984). Seventy-two percent of strokes occur in persons 65 years of age or older (Dyken et al., 1984; Gresham, Duncan, Stason, et al., 1995). It is, therefore, equally important to understand the cultural perspectives of older African Americans. Adults 65 years and older are expected to increase in number to 52.1 million by 2020 and to 68.5 million persons by the year 2050 (U.S. Bureau of the Census, 1995). Although the populations of European Americans will increase, the percentage of African Americans and races other than white is expected to increase in proportion to their populations from 10.2 percent in 1990 to 15.3 percent in 2020 and to 21.3 percent by 2050. By the middle of the 21st century it is projected that nearly half of the population will be African, Hispanic, Asian, and Native Americans, making the terminology of majority and minority essentially meaningless (Huyck, 1993). In particular, it is conservatively estimated that African American older persons over age 65 will increase from 2.5 million to 9.6 million by 2050, making these older persons the fastest growing group of nonwhites (Manuel and Reid, 1982). Given these projected population changes for older African Americans and other persons of color in the United States, the focus of research in several health-related disciplines is on ethnogeriatrics, or the study of cultural variables of persons from diverse ethnic backgrounds as these affect illness and disability (Yeo, 1988).

Ethnicity, often confused with culture, is the component of identity originating from membership in a racial, religious, national, or linguistic group or subgroup, usually through birth. Culture is the whole way of life of the person, of which ethnicity is apart (Barney, 1991). Ethnic identity becomes increasingly important among older people who need to relate to a specific identity and their ethnic roots. Some older adults gain satisfaction from identifying with an ethnic group in a type of symbolic ethnicity. Value is gained from their associations with nuclear and extended families and with close friends, and neighbors who are part of the overall community. A cultural group is a collective of individuals who share common beliefs, ideas, experiences, knowledge, attitudes and behaviors (Huyck, 1993).

A major reason to examine stroke and stroke sequelae within the cultural context of African Americans is that individuals and their families conceptualize a sickness episode within their cultural group framework. Beliefs and behaviors regarding stroke etiology, reasons for becoming ill, perspectives on the diagnosis and methods of treatment, and the roles and expectations of the stroke survivor are influenced in large part by cultural beliefs and by the behaviors, history, and values of the cultural group. In Pachter's 1994 article on "Culture and Clinical Care" (Pachter, 1994), the complexity of personal experiences, family attitudes, and group beliefs determine how decisions are made before, during, and after illness. Most clinical encounters involve an interaction between the culture of health care providers and the culture of the patients. Therefore, individuals from each cultural group often conceptualize health and illness from different perspectives. Unless there is some congruence between these two world views, the health provider and the patient will experience a breakdown in trust, respect, and understanding which, in turn, influences whether the patient will seek care or comply with treatment.

From a review of the related literature on aging, cultural variables that are germane to stroke and post-stroke outcome include ethnic group identification, ethnocultural history with institutions in the United States, pervasive barriers to health care, density of kin and non-kin support, options for treatment of illness, and perceptions of the United States health care system. From the literature on stroke and cerebrovascular accidents, there are four significant areas in stroke and stroke sequelae that are influenced by the cultural context of African Americans. These areas are stroke risks and incidence, severity of stroke sequelae, participation in treatment, and stroke outcome and recovery.

Stroke Risk and Prevalence

Each year, 550,000 Americans suffer a cerebrovascular accident (CVA). Over 150,000 persons die and 350,000 are permanently disabled. Stroke incidence is the number of acute strokes per year. Incidence depends primarily on the age, sex, and racial mix of the population regardless of the number of strokes, the transient nature of the strokes, or the completeness of the strokes.

An important source of diversity for strokes is ethnicity. Black elders as a group are more often ill and disabled and perceive themselves as having poorer health status than whites. The age-adjusted percentage of blacks who report fair to poor health is nearly double that of whites (National Center for Health Statistics, 1995). These perceptions are strongly correlated with inequities in socioeconomic status and resources.

The history of African Americans in this country began with slavery but also included a systematic assault on family life, an eradication of nature African languages and religion, and differential opportunities for education and employment. Although black older adults represent a wide range of differences in income and employment, blacks have lower levels of lifetime labor-force participation and higher unemployment rates due to discrimination. Institutional racism also accounts for older blacks being four to seven times more likely to be functionally illiterate and less likely than whites to have had high-paying salaries, pension, and health insurance. Age-adjusted percentages of chronic disease in persons with low family income less than $14,000 is 5.5 times that for persons with a higher income of $50,000 or more (National Center for Health Statistics, 1995). As a result, older African American adults are also more likely to be malnourished and to experience substandard housing, poverty, poor education, and, therefore, poorer health, than whites (The National Caucus and Center on Black Aged, Inc., 1987; 1994).

Within this context of poverty and vulnerability to health risks, the major cardiovascular risk factor for African Americans is hypertension. That is, less well educated and less affluent African Americans are more likely to have untreated hypertension. High social stress and family instability as well as coping styles and occupational instability have also been implicated in hypertension risks (Secretary's Task Force on Black and Minority Health, 1985).

It is now well established that African Americans, and particularly African American women have the highest rates of hypertension in the United States (National Institute on Aging, 1985; Schoenberg, Anderson, and Haerer, 1988; Cohen, Van Nostrand, and Furner, 1993; Miles and Bernard, 1992). The highest rates of hypertension among blacks occur in the 55-64 age group, where the rate is 51.5 per 100 persons (Anderson, 1988). Miles and Bernard (1992) found that the highest rates of hypertension are among older black women between the ages of 70 and 74. In the New Haven, Connecticut, study, older black women and other nonwhite women reported the highest percentages of high blood pressure diagnoses, followed by white women; however, black and other nonwhite males had the lowest treatment percentages (National Institute on Aging, 1985). Hypertension, may play different roles among African Americans at different ages. A crossover effect reported for blacks in the oldest-old category (85 years and older) is seen to be a positive change in their overall health status. Further study on hypertension indicates that the rates of hypertension in persons over 65 were 474 per 1,000 persons for blacks and 383 per 1,000 persons for whites (Cohen, van Nostrand, and Furner, 1993).

Diabetes, another major stroke risk, is 33 percent higher for blacks than for whites (Morrison and Greeson, 1990). Blacks frequently exhibit and are at higher risk for the complications of diabetes, including heart disease and stroke (Office of Minority Health Resource Center, 1988). Taken together, hypertension and diabetes increase stroke risk for African Americans and at younger ages than for whites. In order words, blacks die or are disabled from the same diseases as whites but at earlier ages (Chirikos and Nestel, 1985).

The increased risk for stroke in older blacks is attributable to cardiovascular factors, another one-third is related to family income, and one-third is unexplained (Gillum, 1988). Stroke rates are reportedly 50 percent higher in African American men than in white men while stroke rates for African American women are 130 percent higher than in white women (National Institute on Aging, 1985). In a 1997 Texas study, women constituted 61 percent of the total stroke deaths at younger ages. This high percentage mirrored the proportion of women to men in the population. African Americans had a threefold to fourfold increased stroke mortality compared to non-Hispanic whites. Mexican Americans, likewise, had a significantly higher rate of stroke mortality at earlier ages (Morgenstern, Spears, Goff, Grotta, and Nichaman, 1997). In another study, African American men and women were found

Table 1

Age-Adjusted Prevalence for Hypertension, Diabetes and Strokes for African Americans and Whites by Descending Order for African Americans, United States, 1986-1990

Condition	AA Women	White Women	AA Men	White Men
Hypertension	19.73	10.96	13.79	10.32
Diabetes	5.07	4.30	4.13	2.45
Stroke	1.20	0.98	1.54	1.14

AA = African American

Source: Centers for Disease Control and Prevention. (1992). Chronic disease in minority populations. Atlanta: Author.

to suffer strokes at nearly twice the rate of whites, particularly for cerebral hemorrhages, cerebral thromboses, embolisms, and subarachnoid hemorrhages (Gaines and Burke, 1995). Interestingly, as blacks and whites grow older, their stroke rates become less significantly different.

Table 1 gives the crude and age-adjusted prevalence for hypertension, diabetes, and stroke for African American and white men and women.

Modifiable risk factors for stroke in African Americans include in order, high blood pressure, smoking, high cholesterol levels, obesity, poor diet, and lack of exercise (Dorfman, 1995). Nonmodifiable factors include a hereditary disposition to hypertension and diabetes. The existence of a biological substrate for hypertension in African Americans has been strongly suggested from clinical trials on medications that are effective in whites but ineffective for blacks (Curry, 1990; Dennis, Welch, Cole, Mendoza, Morgan, Epps, Bernard, and St. Louis, 1997). Other research, however, expands the risk profile for African Americans to include suppressed anger and other forms of internalized responses to racism (Damon-Rodriguez, Wallace, and Kington., 1994), the degree and severity of socioecologic stressors, and socioeconomic inequities. African Americans living in low SES highly unstable neighborhoods were found to have the highest blood pressure levels in a study by Harburg and his colleagues (1973). Younger, black adults under 40 years old living in high stress communities reportedly had a significantly higher percentage of borderline and hypertensive status due in part to their increased efforts to gain control over difficult life circumstances. The same was not true for older African Americans whose biological factors appeared to exert more of a controlling influence in hypertension rather than stress (Syme, 1979). In a related study, a striking relationship between family disorganization and instability and stroke mortality was found to be strongest among black males and females between 35 and 44 years of age (Neser, Tyroler, and Cassel, 1971).

Increased stroke risk is also attributable to the prevalence of Sickle Cell Disease among African Americans. More recent causes of strokes in this population are the result of the acquired immunodeficiency syndrome (AIDS) and substance abuse.

Devastating neurological complications from sickling have been well defined (Taylor and Peters-Johnson, 1988; Wallace, 1993). Payne and Stockman (1979) documented that the sickling of red blood cells during crises cluster in major tissues and organs such as the brain and prevent the blood from freely circulating. Focal brain lesions have been observed in both children and adults with the disease. Kahn and others (1997) investigated factors responsible for stroke in 82 sickle cell patients and identified 19 with a history of stroke.

More than half of all patients infected by the human immunodeficiency virus (HIV) develop central or peripheral nervous system complications from opportunistic infections (Bedos, Chastang, Lucet, Kalo, Gachot, and Wolff, 1995). The prevalence of HIV among ethnic older adults is increasing primarily from unprotected sex, contaminated blood transfusions, and injected drug use (Gordon and Thompson, 1995). Since some physicians are reportedly reluctant to ask older persons about their HIV status, their disease is more advanced when they are hospitalized (Ship, Wolff, and Selik, 1991).

Drug abuse, with the exception of alcohol abuse in older persons, is underidentified (Closser and Blow, 1993), although the drug epidemic is rampant in some African American neighborhoods (Wallace, 1993). Cocaine is particularly toxic to the nervous system and at least one case has been reported of a mature adult who had a stroke as a result of cocaine use (Reeves, McWilliams, and Fitgerald, 1995).

Severity of the Stroke Sequelae

With greater health awareness and advanced medical treatment, mortality rates have declined over the past twenty years. As more persons survive stroke, we can expect an increasing pool of disabled elders who are African American and who will need culturally sensitive and appropriate medical and rehabilitative services. Recent data on 2,930,000 stroke survivors revealed that 31 percent required assistance, 20 percent needed help with walking, and 16 percent were institutionalized (National Stroke Association, 1996).

Over one million Americans have aphasia (Klein, 1995). Recent Stroke Bank Data (Hier, Yoon, Mohr, Price, and Wolf, 1994) indicate that aphasia was present in 19.4 percent of the men and 22.5 percent of the women. Aphasia was more frequent among women with infarcts (37 percent) than in men (28 percent). When the stroke mechanism was accounted for, there were no gender differences in aphasia frequency. Wernicke's global and anomic aphasias were more common in women than in men. Broca's aphasia was somewhat more common men. Although there were no gender differences in infarct size overall, men with aphasia had larger infarcts than women with aphasia. At present, there have been no studies no the epidemiology of aphasia among African Americans.

Other stroke sequelae include altered consciousness, cognitive and deficits, disturbances of vision, and motor and affective disorders. Research has shown that African Americans experience more severe and devastating stroke sequelae than their white age cohorts. African Americans have more severe first-time strokes and return to function more slowly than whites (Miles and Bernard, 1992). Motor impairments, for example, from ischemic strokes, have been found to be greater in blacks than in their white cohorts (Horner, Marchar, Divine, and Feussner, 1991).

African Americans are more disabled from strokes than has been previously recognized. While there is no difference in the medical management of black and white stroke patients, the evolution of physical and functional recovery differs for many black and white patients. Horner and his associates (1991) found that only 13 percent in both racial groups had nonmotor deficits such as speech and language disorders. The greatest physical impairment differences, including ADLs between the racial groups were, however, observed 30 days after admission. Black patients on the average had only two A thirds of normal physical function compared with 95 percent of normal function in whites. Blacks did not approach 90 percent of normal functioning until 90 to 180 days after admission. The apparent racial difference in functional impairments appears to be caused by the severity of stroke at admission as determined by the level of consciousness.

In the Charleston Heart Study (Kell, Gazes, Sutherland, Rust, Branch, and Tyroler, 1989), disability from stroke sequelae was predicted for black females based on elevated systolic blood pressure, high serum cholesterol, and obesity. Systolic hypertension was a major predictor of disability. Incidence of disability was greatest among black females, followed by white females, black males, and white males.

Participation in Rehabilitation for Language Disorders

Given the service needs for African Americans, a major policy question is why this group significantly under uses the health care system. Barriers to the health care system prevent many African Americans from seeking health care that will either reduce stroke risk or limit the severity of stroke sequelae. These barriers include, but are not limited to, structural and economic barriers, cultural barriers, institutional barriers, and policy level barriers (American Society on Aging, 1992).

Economic and Structural Barriers

Economic and structural barriers include access to Medicare and private health insurance plans, availability of transportation, and location of health services. Some African American older adults have been restricted to service sector employment during their working years and are not insured or, they may be ineligible for Medicare because of frequent unemployment. Lack of insurance or inadequate coverage often determines whether persons at risk for stroke feel that they can afford to seek care. In 1990, African American elderly had the highest rates of poverty of all other nonwhite groups. Although elderly African Americans are similar to elderly whites in having no insurance, they are much more likely to depend solely on Medicare. About 38 percent of older African Americans have no insurance other than Medicare. Even with Medicare, out-of-pocket expenses for deductibles, copayments, and uncovered services such as outpatient drugs and long-term care, create a considerable barrier to low-income black elders (Neighbors and Jackson, 1986; Gibbs, 1988; Petchers and Milligan, 1988; Damon-Rodriguez et al., 1994). However, when African Americans and whites have equal third-party coverage, they have similar patterns of use of inpatient medical and rehabilitative services as well as community health and social services (Link, Long, and Settle, 1992; Horner, Hoenig, Sloane, Rubenstein, and Kahn, 1997).

Structural barriers, such as proximity of services and lack of transportation, prevent older blacks from seeking and remaining in health care. African Americans tend to use health care services that are strategically placed within their communities (Dillard, Andonian, Flores, Lai, McRae, and Shakir, 1992). Wallace and Freeman (1990) and Davis (1976) observed that African Americans adults in urban areas gave lack of transportation as major reasons for their decisions to decline post-stroke clinical care for language disorders.

Cultural Barriers

Cultural barriers are derived from differences in health beliefs and expectations and responses to the health care system. Early health beliefs direct the approaches taken by older adults to cope with a health crisis. Older African American adults may exercise a number of treatment options derived from childhood experiences (Barker, 1994) and may turn to close friends and family for advice or may attempt to treat themselves before turning to their physicians or therapists for care. Lack of compliance with taking prescribed medications for hypertension may also be tied to the person's feeling better. The older black patient may discontinue taking medication if feeling better is equated with being cured (Richardson, 1988).

The extent to which African American adults rely on folk remedies is unknown. However, the most consistent folk healer documented is the "old lady" or "Big Mama" who treats health problems with a variety of over-the-counter drugs, herbs, roots, and turpentine (Snow, 1981; Richardson, 1988). Fear and distrust of doctors and medical procedures have intensified since the Tuskegee Study became public knowledge. In that experiment, African Americans with syphilis were used as human guinea pigs and denied treatment although one was available. This study reinforced the perception among blacks that traditional medicine or government-sponsored research studies cannot be trusted.

There is also the cultural impact of religiosity. Approximately 90 percent of poor elderly blacks maintain church affiliations and the role of religion in health and illness is very important (Taylor, 1986; Richardson, 1990). For example, some African American older adults subscribe to the beliefs that their illness is in God's hands and that prayer and the laying on of hands for healing can replace modern medicine.

An explanatory model for some black older persons may be one of natural versus unnatural illness. Natural illness is caused by not taking care of one's body. Unnatural illness, however, is believed to be caused by roots, witchcraft, or voodoo. Hence, the more the individual visits the doctor to cure an unnatural illness, the more ill the person will become (Snow, 1981). If an illness extends over a long period of time and is not immediately diagnosed, the patient may conclude that the illness is unnatural.

Lack of education about the aging process can also be a cultural barrier for the patient and the family. It is not unusual for families to mistake the warning signs of a stroke as the patient's feeling tired or just getting old. Treatment for the stroke may be delayed until the symptoms are unmistakable. Delays in getting to the hospital can exacerbate the effects of the stroke.

Institutional and Policy Barriers

Another possible explanation for differences in stroke sequelae between whites and blacks is that there are disparities in how blacks and whites are treated by health care providers. Rubenstein and Kramer (1994) found that, for cardiac procedures, whites received more electrocardiograms, treadmill and angiographic examinations, and somewhat fewer echocardiograms than blacks. African Americans and women are less likely to be seen in the hospital by a specialist in neurology and neurosurgery than white men (Horner et al., 1991). Similar differences have been found in the rates of coronary artery bypass surgery nationally across racial groups and the use of diagnostic procedures appropriate for older patients (Goldberg, Hartz, Jacobsen, Krakauer, and Rimm, 1992).

Because of their histories in this country, African Americans will reject a health care system that they feel is racist or indifferent. Perhaps the best examples of the impact of institutional barriers are: (1) where the hospital and clinical staff, in the main, do not reflect the ethnocultural diversity of the patients served; (2) outreach to the community has appeal to the general population only; (3) the hospital and clinical staff are not knowledgeable about or do not respect the cultural variables that affect health care decisions; and (4) administrative procedures and paperwork are considered to be too complicated to negotiate. These factors send a message to many African Americans that the services are inappropriate for them and they, in turn, reject the services. Policy barriers in which the patient sees a different doctor or clinician at each encounter are extremely disconcerting for older persons who find it difficult to adapt to change, and eventually discontinue participation (Payne, 1997).

Occupation therapy research has addressed effective ways to encourage African Americans to remain in treatment through culturally sensitive activities and clinician training. Culturally focused programming, flexible programs, and a culturally competent staff have been used effectively to provide quality health care in a multicultural community (Dillard et al., 1992).

Cultural issues that can determine whether African Americans seek or remain in post-stroke language rehabilitation post-stroke are the types of tests and materials used to evaluate competence. There are two broad categories of tests to assess post-stroke language function. Traditional tests of aphasia which measure language disabilities in all modalities, including speaking, understanding, reading, writing, and simple arithmetic, are most commonly used with post-stroke survivors. Less commonly used but more relevant to measuring functional outcome for reimbursement are the functional measures of communication in daily living. These tests share in common the use of auditory and visual stimuli to elicit a response from the patient. The functional assessments are perhaps most related to the cultural environments of the patient's everyday communicative needs. However, the tests of aphasia also draw from the perceived needs of patients to be able to use language efficiently to make their wants and needs known and to remain independent.

Several problems complicate the appropriateness of these tests for African American patients. With the exception of three tests, most functional and aphasia tests do not report that African Americans were included in the field-test data. Therefore, any relevant information about this population that is applicable to the test stimuli or to the test scoring is not available. The visual stimuli in aphasia tests show white persons in situations that are not relevant to urban blacks. Further, the auditory stimuli given in situations for complex ideational and vocabulary assessment are far removed from the everyday contexts of most African Americans. Table 2 gives the most commonly used tests of functional communication and aphasia. An asterisk is placed beside those tests that include African Americans in the field-test data.

As can be seen from Table 2, none of the authors of the traditional tests of aphasia report that their normative data included African Americans; however, three of the functional communication test authors did indicate diversity in their subject population. Unfortunately, two of the functional instruments, the CADL (Holland, 1989) and the ASHA FACS (Frattali, 1995) sampled their populations in numbers too small to determine whether ethnicity had a bearing on the stimuli used. Only one test, the Communication Profile (Payne, 1994), used equal numbers of African Americans and whites and did find that ethnicity mattered in five out of 26 functional communication items considered to be important to the field-test subjects. Those five items were, for white Americans, "Telling the

Table 2

Selected Commonly Used Aphasia and Functional Communication Instruments and Indication of Including African Americans in the Normative Sample

Type of Assessment	Assessment
Aphasia Diagnostic Evaluations	Boston Diagnostic Examination of Aphasia (BDEA) (Goodglass & Kaplan, 1983)
	Boston Assessment of Severe Aphasia (Helm-Estabrooks, Ramsberger, Morgan, & Nicholas, 1989)
	Neurosensory Center Comprehensive Examination for Aphasia (NCCEA) (Spreen & Benton, 1969)
	Western Aphasia Battery (WAB), Kertesz, 1982)
	Porch Index of Communicative Ability (Porch, 1971)
	Minnesota Test for Differential Diagnosis of Aphasia (MTDDA) (Scheull, 1965)
Functional Communication Assessments	Functional Communcation Profile (FCP) (Sarno, 1969)
	Communication Abilities in Daily Living (CADL)
	Patient Functional Communication Screening Instrument (FCS) (Toner, Gurland, & Gasquoine, 1984)
	The Functional Life Scale (FLS) (Sarno, Sarno & Levita, 1973)
	Communication Profile: A Functional Skills Survey (Payne, 1994)*
	Functional Assessment of Communication Skills for Adults (AHSA FACS) (Fratalli, Thompson, Holland, Wohl, & Ferketic, 1995)*
	Communicative Effectiveness Index (CETI) (Lomas, Pickard, Bester, Elbard, Finlayson, & Zoghaib, 1989)
	Revised Edinburgh Functional Communication Profile (EFCP) (Wirz, Skinner, & Dean, 1990)

*Author indicates that African Americans were included in the normative sample for the assessment.

date," and for African Americans, "Understanding your bills and the amounts due," "Reading the message on a greeting card," "Naming your personal belongings," "Understanding when someone asks for help," and "Reading signs on a door" like "exit" and "push."

Whether the aphasia or functional communication tests that have not included sufficient numbers of African Americans in the normative data are indeed appropriate for the population has not been systematically investigated. The effects of test bias can be extrapolated from a test of cognitive and language skills. Although not typically used for language testing with stroke patients, the Mini-Mental State Examination (MMSE, Folstein, Folstein, and McHugh, 1975), for example, which did not include African Americans in the normative data, is now considered to be too culturally and ethnically biased for use with diverse populations. According to their test results on the MMSE, African Americans were consistently reported to be significantly more cognitively impaired than whites. When education and ethnicity were considered in the scoring, African Americans received higher scores comparable or better than Whites (Molgaard, Stanford, Morton, Ryden, Schubert, and Golbeck, 1990).

It is reasonable to assume, therefore, that African Americans with aphasia have been inappropriately diagnosed as well and that these misdiagnoses served to bias clinician perceptions of the patient and the patient's skin. Clinician misinformation and bias based on inappropriate test results have enormous implications for aphasia treatment, which is predicated on the language deficits determined from testing. If the test results are inappropriate, it is probable that the treatment strategies will not produce the desired results. An excellent example of the effect of misinformation on diagnosis and treatment is given by Holland (1983) as an anecdotal description. In the case of Mrs. S, an African American patient with dysarthria, a misdiagnosis of a "black dialect" was documented by the clinician although her family spoke Standard English. While Holland does not elaborate on the prescribed treatment, it is likely that the clinician planned to treat the Mrs. S for her dialectal differences instead of treating her neurogenic speech disorder.

Additional issues influence the participation of African Americans in language therapy. Davis (1976) found that the acceptability of language services determined whether respondents elected to attend treatment. A determination of acceptability in her study had strong overtones of prejudice and stereotyping from clinical service providers. Because African Americans have been underreported in the clinical and research literature, clinicians may treat aphasia without understanding the cultural dynamics of their patients. It is inevitable that some patients and their families will interpret this cultural dissonance between service provider and patient as racism and discontinue therapy.

Stroke Outcome and Recovery

Stroke outcome and recovery are dependent largely on severity, location, and complications of the stroke and the age of the stroke survivor. Prognosis is also dependent on whether outpatient stroke survivors have professional services available in the home, obtain regular medical care, participate in rehabilitation programs for language and motor disorders, and attend supportive and counseling sessions. European Americans tend to use health care services in greater proportions to their populations than African Americans (Centers for Disease Control and Prevention, 1992). Whites have the highest percentage of regular home health care use (Mui and Burnette, 1994) and are less likely to under use health services because of cost or because their health plans do not cover specific services (Centers for Disease Control and Prevention, 1992). In contrast, African Americans tend to under use all types of health services and support groups which places them at risk for poor outcome. African Americans have lower rates of use of formal in-home care compared to whites and tend to know less about community services. Minority representation in the planning and administration of community-based services is notably low, which may contribute to the lower rates of utilization (Wallace, Andersen, and Levy-Storms, 1993; Damon-Rodriguez, Wallace, and Kington, 1994). Other possible explanations for differences in participation in post-stroke services are that: (1) African Americans often choose episodic care over routine, preventive care; (2) there is greater density in kin- and non-kin networks which may either replace or augment traditional health care; (3) the location of support groups outside of the community may pose a barrier to older blacks; and (4) counseling services may be viewed as shameful or, at best, an invasion of privacy.

Although African Americans visit their doctors more frequently than whites, studies have found that elderly African Americans use emergency room care as a source of primary health care at a significantly higher rate than whites. Emergency medicine is costly and cannot provide comprehensive geriatric assessment, continuity of care, or simultaneous treatment of chronic conditions to prevent a reoccurrence of stroke (Browkow and Zaraa, 1991).

African Americans also report greater frequency of family contact and family and nonfamily support in times of illness than whites. Unmarried older African Americans are twice as likely to live with family than whites. The density of the support network not only includes blood-related family members but also can include church members, neighbors, and persons who are as close as family, or fictive kin. However, the myth of "they take care of their own" is based on an idealized view of the traditional family as providing all that the patient needs. It is more likely that families cluster together out of their cultural expectations and economic need (Richardson, 1990) but are unable to provide the level of support needed by the recovering stroke patient. The support network does function in assisting the post-stroke patient to remain at home. Blacks are much less likely to reside in long-term care facilities and more likely to remain in the community than whites. This extensive support network also has some advantage for providing emotional support when the patient participates in rehabilitation services.

African Americans are frequently uncomfortable with mental health services or counseling (Hu, 1991) and may perceive the need for these services as a sign of weakness or as an invasion of personal privacy. The location of supportive and counseling services in proximity to the patient, such as adult day care centers and stroke support groups located within walking distance to the patient's neighborhood are important factors in whether African Americans use these services.

Conclusions and Recommendations

African Americans are most in need of a variety of health care services because of their chronic disease histories and stroke rates. Within the United States, blacks have the highest rates of hypertension and diabetes of any ethnic group. Their cardiovascular risk factors are similar only to Mexican Americans in their severity and frequency. Despite increased risks for stroke, however, more persons within the African American community are surviving with disabilities. Because access to health care is a critical factor in stroke incidence, severity of stroke sequelae, and stroke recovery, barriers to health care continue to be major public health concerns for African Americans.

Cultural variables determine whether African Americans are comfortable with formal health care services (Payne-Johnson, 1992). A number of cultural and logistical barriers prevent this population from accessing the system to prevent or ameliorate stroke disabilities. Table 3 gives recommendations for providing quality care to African Americans.

Table 3

Recommendations for Quality Care of African Americans at Risk for Stroke and African Americans who are Post-Stroke Patients

Number	Recommendation
1	Health care professionals should be sensitized about the cultural variables of African Americans that affect their decisions for care.
2	Health care professionals should be educated about appropriate and sensitive approaches to service delivery.
3	Researchers need to include African Americans in clinical trials and research in greater numbers.
4	Researchers need to modify the field data of existing tests for aphasia and functional communication to include African Americans in greater numbers.
5	Clinicians should adopt care models to eliminate structural barriers such as out-of-community location and lack of transportation.
6	Clinical administrators need to remove financial barriers to therapy imposed by the long-standing history of discrimination and racism in this country through sliding fee scales and reassessment of costs for services.
7	Clinical administrators should simplify written and oral procedures for admission to rehabilitation facilities.
8	Clinical administrators should develop a facility advisory group made up of representatives from their service and professional communities to evaluate the cultural appropriateness of testing and treatment strategies.
9	Clinicians should take care to conduct culturally sensitive intake and case history information that includes family arrangements, daily communication skills needed in the everyday context, and culturally derived beliefs about health and disability.
10	Clinicians should modify existing aphasia tests to include an extensive language sample from African American patients.
11	Treatment approaches should incorporate the patient's cultural preferences for leisure activities, styles of intrafamily communication, and other functional needs.

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CONTEMPORARY ISSUES IN ACUTE STROKE: IV TPA FOR ISCHEMIC STROKE

Roger L. Weir, M.D.

In December 1995 the academic (1) and lay press reported improved stroke outcomes with the use of intravenous tissue plasminogen activator (iv tPA). With multiple evaluations there was a 25 to 50 percent improvement over the results of placebo. It was called the first successful treatment for ischemic stroke. There have been problems in achieving widespread usage of this therapy (3). The limited success of iv tPA in the European Cooperative Acute Stroke Study (ECASS) (4) has further made some physicians hesitant in their use of iv tPA.

tPA will bind to blood clots and then catalyze destruction of the clot. This has been done successfully with coronary arteries in treatment of acute myocardial infarction. Similarly tPA has been successfully given intra-arterially to restore circulation in acute cerebral ischemia. When given intravenously for thrombotic stroke, it can reopen occluded blood vessels.

Cerebral arteriolar occlusion will induce death in the central core of ischemic tissue. Peripheral tissues with a reduced blood supply (the ischemic penumbra) can recover significantly if perfusion is restored within six to twelve hours. Delay in reopening occluded cerebral vessels will be associated with increased neuronal damage and more extensive infarction. Thus, a prompt clot lysing effect is needed for simple therapeutic efficacy.

The clot lysing ability of tPA can lead to dangerous bleeding, including intracranial hemorrhage. At present, tPA must be started within three hours of stroke onset. After three to four hours of cerebral ischemia, there is a tendency of thrombolytic agents to induce hemorrhage (2,7). In the NINDS trial, symptomatic hemorrhage occurred in 6.4 percent of patients given tPA but in only 0.6 percent of patients who received placebo.

Thus both the efficacious and safe use of tPA for ischemic stroke require promptness. A detailed evaluation and screening of the potential patient is essential (2). The acceptance rate for screened patients in the NINDS study (1) was three to four percent. Though the qualifying rate has reached 10 percent in at least one instance, the overall qualifying rates are quite low. The problems involved in achieving rapid, safe and appropriate use of tPA have been studied and detailed (5,6).

It is valuable to use a detailed EXCLUSION LIST, to make sure the myriad dangers are avoided. Several of these lists are available in the literature. Major source data for these exclusion criteria are: the American Heart Association guidelines (2), the original publication (1), and the package insert for tissue plasminogen activator (activase brand of alteplase, Genentech).

All exclusion/inclusion criteria are intended to exclude patients who may bleed, or who would not have a clear benefit by taking an intimidating drug like iv tPA. Early arrival of the patient to the Emergency Department is critical. One hour is required to examine and properly evaluate patients. Most patients arrive in emergency rooms more than two hours after their stroke. Table 1 is a flow outline, which shows the activities involved in management of the tPA patient.

Table 1

Patient Movement and Activity with tpa Treatment

LOCATION	EXPECTED ACTIVITY
EMERGENCY DEPARTMENT	EVALUATIONS (NURSE, MD, NEUROL.) **EXCLUSION LIST** INFORMED CONSENT BLOOD DRAWING
CT SCAN	**CT SCAN** MONITOR PATIENT
EMERGENCY DEPARTMENT	CT SCAN RESULT LAB RESULTS **GIVE tPA** MONITOR PATIENT
MICU	MONITOR: NEUROL., BP, BLEEDING
INTERMEDIATE CARE UNIT	CT SCAN, MONITOR NEUROL., BP, BLEEDING
WARD	MONITOR: NEUROL., BP, BLEEDING
HOME	SEE ROUTINE CVA PROTOCOL

Before giving tPA a CT Scan is needed to show that the cerebral lesion is not hemorrhagic. An evaluation for multitudinous hemorrhage risks must be carried out. Some of these risks are: recent major surgery, recent gastrointestinal or urinary bleeding, recent lumbar puncture, symptoms of subarachnoid hemorrhage, elevated prothrombin time or recent stroke. Continuous observations for bleeding and maintenance of blood pressure 185/110 or less are carried out.

More widespread use of tPA requires earlier arrival of patients to hospital. Subsequently, early access to the CT Scan, and laboratory tests is essential. Advance planning, urgency and cooperation are central to success. When stroke patients do arrive early, they may have more severe neurologic deficits (5,6). In our institution many early stroke arrivals have had an intracerebral hemorrhage. Improved recognition of early or milder strokes by the lay public is needed.

Modifications in patient behavior, emergency systems, and stroke evaluation will be required to maximally utilize tPA. These adjustments in timeliness, use of stroke scales, efficiency in workup, will benefit acute care for neurological disorders, even when tPA use is not being considered.

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CONTEMPORARY ISSUES IN ACUTE STROKE: INTRACEREBRAL HEMORRHAGE

Roger L. Weir, M.D.

Intracerebral hemorrhages constitute five to 15 percent of all strokes and have a 30-day mortality of 30 to 50 percent. Acute health care costs, and subsequent costs are high in comparison with ischemic strokes. African-Americans have an incidence of intracerebral hemorrhage more than double that of white Americans, but less than half that of Japanese (1).

Hypertension is the principal risk factor for spontaneous intracerebral hemorrhage. The ruptured blood vessels are penetrating arterioles of 50 to 200 microns in diameter. Hypertension induces fibrinoid necrosis and hyaline degeneration of arterioles. Charcot-Bouchard microaneurysms develop in these vessels and these aneurysms are liable to rupture. Other causes of intracerebral hemorrhage are arteriovenous malformations, anticoagulant use, amyloid angiopathy, berry aneurysm rupture, stimulant drug abuse and blood dyscrasias. Sites of intracerebral hemorrhage in order of decreasing frequency are: putamen, thalamus, cerebral white matter, cerebellum and pons. Fifteen percent of hematomas occur in the posterior fossa, with most of these occurring in the cerebellum. Cerebellar hemorrhage may particularly constitute an emergency due to risk of tonsillar herniation and death.

With intracerebral hemorrhage symptom onset is typically sudden and severe. Focal neurological deficit is accompanied by headache in 70 percent of cases. Loss of consciousness and signs of meningeal irritation occur in some patients. At lumbar puncture there is evidence of CNS bleeding in over 90 percent of cases. CT Scan is essential if intracerebral hemorrhage is to be consistently differentiated from ischemic stroke. CT Scan can also show evidence of increased intracranial pressure, intraventricular blood, herniation, and hydrocephalus.

Hematomas are classified as smaller (<20-25cc), or larger and superficial or deep. The prognosis for small or superficial hemorrhages has been better than that for large or deeply situated lesions. Hematoma size can be easily estimated (2). A study by Tuhrim et.al, (3) identified the independent risk factors for a poor outcome as: increased size of lesion, initial Glasgow Coma Scale <=eight, increased systemic pulse pressure and presence of intraventricular bleeding.

Intracerebral hemorrhage produces its adverse effects via: a local mass effect, increased intracranial pressure, decreased cerebral blood flow, edema induction, obstruction of ventricles, and leaking of blood into the ventricles. Evidence of increased intracranial pressure may be obtained clinically or from brain MRI or brain CT. However, specific intracranial pressure monitoring is more definitive.

Medical treatments have focused on maintaining normal perfusion of brain tissue by reducing both cerebral edema and increased intracranial pressure. These treatments have included patient posture, mannitol, glycerol, diuretics, fluid restriction and lowering the pCO_2 by hyperventilation. Steroids are used but their value has been debated. Patients may show a compensatory elevation in blood pressure to maintain cerebral perfusion in the face of increased intracranial pressure (Cushing reflex). Mean arterial blood pressures outside the patient's range of cerebral autoregulation may be associated with cerebral hypoperfusion or hyperperfusion. Cerebral hypoperfusion is more documented as a cause of patient morbidity and mortality. Cerebral autoregulation is normally maintained with mean arterial blood pressures (MABP) of ~70 to 140mm Hg. With long term hypertension, the range of autoregulation is shifted upward. The MABP must equal the sum of an adequate cerebral perfusion pressure (50-70mm Hg.) and the patient's increased intracranial pressure (up to 35 - 50mm Hg.) Surges in intracranial pressure due to pressure waves make appropriate management even more difficult.

Surgical evacuation is performed for some intracerebral hemorrhages. Despite much study, the criteria for surgical intervention are unclear. Ventricular obstruction is a clear indication for surgery. Patients who are deteriorating due to the mass effect of blood plus increasing edema may be surgical candidates. Hemorrhages in the nondominant hemisphere are more appropriate for surgery. Hemorrhages in the cerebellum =>3cm. are often managed surgically, and may constitute real emergencies. Stereotaxic surgery with even partial evacuation of a clot can retard deterioration and improve patient prognosis.

Many older reports accepted a short (momentary or several minutes) duration of bleeding in spontaneous intracerebral hemorrhage. However, recent studies have shown ongoing bleeding for several hours (2.5 to 24) in about a third of cases (4,5). This period of persistent bleeding represents an opportunity for appropriate therapeutic intervention. Reduction of this bleeding should reduce the size of the hematoma and the volume of edema that develops.

Cessation or prevention of bleeding are dominant aims in the management of aneurysmal subarachnoid hemorrhage (SAH). Direct surgical attack of aneurysms has been most successful. However, the site and source of bleeding with cerebral aneurysms are much more definable and accessible. Other methods of stopping bleeding in aneurysmal SAH have had limited success. These methods have included: use of epsilon amino caproic acid, common carotid ligation, aneurysm wrapping, and lowering of blood pressure.

Management of blood pressure following intracerebral hemorrhage has been a subject of extensive debate and disagreement (6,7). Nevertheless the documented continuous bleeding (above) suggests that very early lowering of blood pressure in patients with intracerebral hemorrhage may reduce bleeding and thus improve prognosis. Adequate cerebral perfusion in normal individuals should be achieved with an MABP of about 75mm Hg. Which specific blood pressures or resultant cerebral perfusion pressures would be most efficacious in a variety of patients with intracerebral hemorrhage is not defined. Zabramski (1) has recommended a systolic blood pressure of 150-170mm Hg, with treatment beginning in the emergency room. Sila (8) advises a systolic BP of 150mm Hg. with individualization depending on the intracranial pressure. Other sources have quoted no figures but recommend that blood pressure be gradually lowered over days.

It seems probable that management of intracerebral hemorrhage will continue to move in the direction of prompt lowering of blood pressures. This should be done with ongoing neurological monitoring. Definitive studies or descriptions of morbidity/mortality at specific lower blood pressures will probably be needed to retard this change.

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CONTEMPORARY ISSUES IN ACUTE STROKE: BASIC MECHANISMS AND EVOLVING THERAPY

H. Branch Coslett, M.D.

The term stroke refers to the clinical condition in which neurons die, usually as a consequence of insufficient blood supply. The term encompasses a number of different conditions including ischemic infarction, intracerebral hemorrhage, and subarachnoid hemorrhage. As ischemic infarcts comprise approximately 85 percent of all strokes, the following discussion will focus on this type of stroke.

Ischemic strokes can be subdivided according to the presumed mechanism by which the blood supply is interrupted. Strokes which are caused by the accumulation of atherosclerotic plaque and other types of debris with a resultant blockage or significant interruption of blood flow are designated "thrombotic strokes," strokes which are caused by a blood clot or other materials which are transported in the blood only to a lodge in a vessel, thereby preventing blood flow are designated "embolic strokes." Most embolic strokes are caused by clots which arise in the heart or in the large vessels leading to the brain such as the carotid artery. Finally, some clinicians distinguish between "large vessel" and "small vessel" or "lacunar" infarcts; large vessel strokes tend to involve substantial volumes of cortical and subcortical tissue whereas small vessel strokes tend to be rather small, typically measuring less than 2 cm. in diameter. Small vessel or lacunar strokes often involve white matter deep in the brain, the brainstem or subcortical gray matter structures such as the thalamus or the basal ganglia. Although the distinction between large and small vessel strokes remains controversial, many clinicians believe that fundamentally different pathologic processes give rise to extensive strokes in the territory irrigated by large blood vessels as compared to the small volumes of infarction caused by the occlusion of small arterioles deep in the substance of the brain or the brainstem.

A number of risk factors for ischemic infarction have been identified. Some of these risk factors, such as age, gender, heredity and race or ethnicity, cannot be altered. There are, however, a number of important risk factors for stroke which can be modified. Hypertension is the most common modifiable determinant of stroke incidence; the risk of stroke rises in direct proportion to blood pressure. Effective and well-tolerated antihypertensives have contributed to a substantial reduction in the incidence of stroke over the last several decades. Diseases of the heart, including atrial fibrillation, impaired myocardial contractility (e.g., cardiomyopathy) and diseases of heart valves, are associated with major increases in the incidence of stroke. Additional important modifiable risk factors for stroke include, Diabetes Mellitus, smoking, hyperlipidemia, and excessive alcohol consumption.

Traditionally, most therapies for stroke have been directed toward stroke prevention. The most widely used treatment for stroke prevention continues to be aspirin which serves to block platelet aggregation; ticlopidine (Ticlid) has also been employed for this purpose. In those instances in which a stroke is thought to be embolic in etiology, anticoagulation is often employed. Heparin is typically utilized in the acute phase whereas warfarin (Coumadin) is employed if long-term anticoagulation is deemed necessary. Finally, carotid endarterectomy is usually recommended in patients with Transient Ischemic Attacks or stroke who are found to have a reduction of the lumen of the carotid artery of 70 percent or more.

Research in recent years has greatly expanded our understanding of the basic mechanisms of neuronal injury and death in ischemic stroke. One consequence of the evolving understanding of the processes by which a reduction in blood supply ultimately leads to cell death has been the development of a number of potential therapies which target specific stages in the "ischemic cytotoxic cascade" which culminates in cell death. Before briefly discussing these potential therapies, the processes comprising the ischemic cytotoxic cascade will be briefly described.

As illustrated in Figure 1, the initial consequence of a reduction in blood flow is the depletion of energy stores within the cell. This leads to acidosis and the failure of the sodium/potassium pump of the cell membrane; these processes lead, in turn, to a depolarization of the cell membrane. At least two deleterious consequences of membrane depolarization may be identified. The first is the opening of voltage-operated calcium channels leading to an increase in intracellular calcium ions. The second is the release of the neurotransmitter glutamate and the resultant overstimulation of NMDA and AMPA receptors. This stimulation also causes an elevation in intracellular calcium ions which impairs mitochondrial function, thereby worsening the depletion of intracellular energy stores.

Increased intracellular calcium load also activates nitric oxide (NO) synthetase as well as enzymes that degrade proteins, phospholipids and nucleic acids. This process leads to the formation or "free radicals" which cause cell death.

As previously noted, a number of therapies have been developed which target specific stages in the ischemic cytotoxic cascade. For example, several compounds which selectively effect voltage-gated cell membrane channels have been developed. Phenytoin and phosphenytoin block sodium channels, thereby reducing the release of glutamate. Additionally, nimodipine, a potent calcium channel blocker, has been found to be useful in the treatment of subarachnoid hemorrhage and may be of utility in the treatment of ischemic infarction.

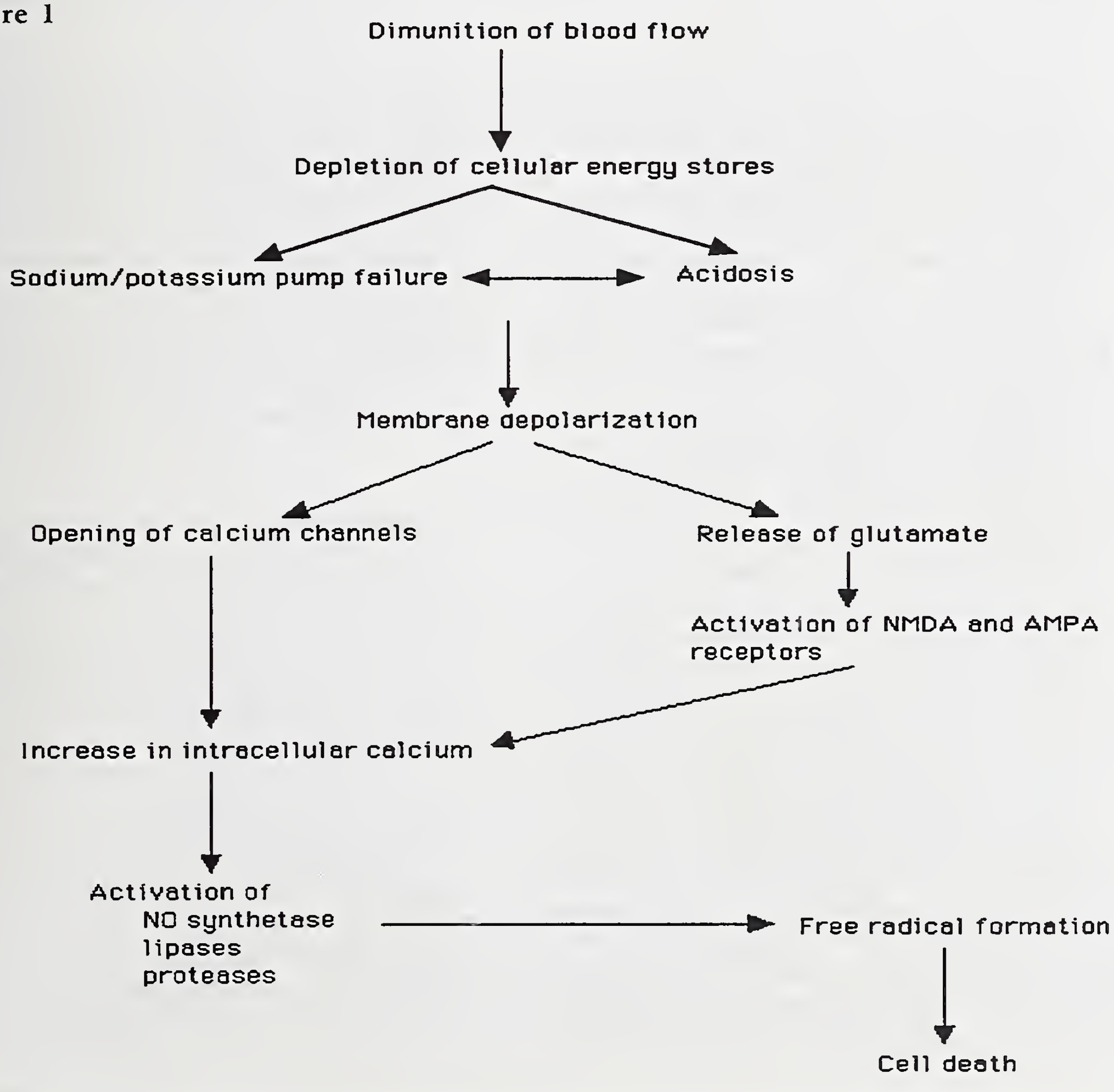
As activation of NMDA receptors has proven to be an important step in the ischemic cytotoxic cascade, several NMDA receptor antagonists or modulators have been tested in clinical trials. Although these compounds have appeared promising in animal studies, their utility in humans has been limited by significant side-effects including agitation, hallucination, and paranoia.

Compounds which neutralize free radicals have also been employed in clinical trials. One such compound, tirilizad mesylate, has been studied in several large trials, thus far with disappointing results. Membrane stabilizing agents such as piracetam appear to show promise as an early treatment for ischemic infarction.

In this context it must be emphasized that only a small sample of the novel potential therapies for ischemic stroke were mentioned above. A number of other agents have been tested and newer agents are under development. Although the specifics of these agents is beyond the scope of this note, the important point is that recent insights into the fundamental pathologic processes initiated by cerebral ischemia have resulted in the development of a number of new therapies targeting specific stages in the ischemic cytotoxic cascade. Either as monotherapy or in combination with existing or other emerging therapies, these treatments will in all likelihood offer the potential to improve outcomes from stroke.

Finally, one factor which may ultimately limit the efficacy of the therapeutic approaches described above must be acknowledged. Profound ischemia leads to cell death within minutes; when subjected to a lesser reduction in blood flow, the window of opportunity for the prevention of cell death may be as long as 10-12 hours. Not surprisingly, then, many investigators have reported an inverse correlation between the interval from onset of symptoms to initiation of therapy and outcome measures such as severity of motor deficit. Substantial improvements in the availability of medical services and the rapidity with which those services are delivered will be critical if the promise of the agents under development is to be fully realized.

Figure 1


Dimunition of blood flow
Depletion of cellular energy stores
Sodium/potassium pump failure
Acidosis
Membrane depolarization
Opening of calcium channels
Release of glutamate
Activation of NMDA and AMPA receptors
Increase in intracellular calcium
Activation of
NO synthetase
lipases
proteases
Free radical formation
Cell death

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CULTURAL ISSUES IN THE DESIGN OF RESEARCH ON SPEECH AND LANGUAGE DISORDERS RESULTING FROM STROKE AND OTHER NEUROLOGICAL IMPAIRMENTS

Orlando L. Taylor, Ph.D.

A universally accepted axiom of a communication disorder is that such disorders are defined from the vantage point of what is considered to be normal communicative behavior. An equally accepted universal axiom is that normal communicative behavior is centered within a cultural context. These rather basic notions lead us to an obvious conclusion—research on speech and language disorders sequelae to stroke and other neurological impairments within any population must consider cultural issues in order to achieve valid results.

Over the past three decades, a considerable volume of research in communication sciences and disorders has focused on cultural issues. Much of this research has centered, however, on normal and pathological aspects of speech and language behavior in children. Moreover, this research has focused largely on communicative disorders that are thought to have functional or non-organic etiologies. Indeed, one might conclude, albeit erroneously, from the literature that cultural issues are of little importance in understanding the nature and treatment of communication disorders in adults or of such disorders resulting from physical causes. Taken to its obvious extreme, this conclusion suggests a “one size fits all” approach to studying—and treating—these disorders. Such conclusions are unsupported by facts.

Two difficult and complicating factors in conducting culturally sensitive research on a given population are: (1) cultural groups are rarely, if ever, homogeneous in makeup and (2) cultural groups rarely, if ever, differ totally from other groups in society. Because of these realities, research on speech and language disorders resulting from stoke and other neurological impairments in African Americans—or in any other group for that matter—must always consider the heterogeneity factor. Unfortunately, much of the research on communication disorders in African American and other neglected and disenfranchised populations in the United States has focused on the lowest income and least educated segments within these populations—and the results have all too often been generalized to the entire group. With respect to the middle class segments of these populations, there has often been an unspoken assumption that individuals within these segments are “just like everyone else.” These assumptions lead to stereotypes and bad science. Not only are African Americans—like every other cultural group of Americans—heterogeneous with respect to class, education and communicative behavior, but rather paradoxically the middle class segment of the population frequently retains elements of culturally identifiable communicative behavior for use when code switching is appropriate or desired.

An equally disturbing and inappropriate situation is seen when researchers compare or contrast data from the low income and least educated segments of the African American or neglected community with middle class, white populations using tasks or instruments reflective of the latter culture. Many years ago, Lorraine Cole of the American Speech-Language-Hearing Association described this type of research as "victim analysis" in view of the predicted outcomes which revealed either poorer levels of performance by African Americans or differences in communicative behaviors or disorders, or the incorrect attribution of communicative differences to race or culture when they, in fact, should be attributed to socioeconomic status. It is because of these—and other—complicated factors that culturally sensitive research on communicative disorders in African American and other culturally diverse populations not a simple matter.

Recommendation 1:

NIDCD should fund no research on communicative disorders resulting from stoke or other neurological impairments in African American or other culturally or linguistically diverse groups which presume in-group homogeneity or that makes comparisons across cultural groups without controlling for socioeconomic class and education.

Etiological Considerations

Because aphasia and related disorders are caused by neurological impairments, it may seem reasonable at first glance to presume that because neurological architecture and function are the same throughout the human species that culture—and even race—are of minimal or no consequence in studying and treating these disorders. However, there are a number of factors that could have direct cultural—and racial—bearing on the subject. To begin with, there is the matter of etiology. While it is well known, for example, that stroke is a major cause of speech and language disorders, it is also well known that stroke, especially associated with hypertension, is particularly prevalent in African American communities. And, it is equally well known that the traditional high fat diet of many African Americans may be a contributing factor to hypertension.

Moreover, there are certain disease entities, e.g., sickle cell disease, that have greater prevalence in African Americans than in other populations that may cause stroke and other neurological impairments leading to speech and language disorders. In 1975, Williams reported that one in every 10 to 12 African Americans in the United States carry the sickle cell trait, and that one in every 600 has sickle cell disease. In their landmark study, Payne and Stockman (1979) reported that the sickling of red blood cells impedes or halts the blood supply to vital body organs and tissues, including those related to normal speech and language function.

Etiological factors are not just limited to physical considerations. Recent research findings are reported, for example, that claim that stresses associated with racism are contributing factors to the physical health of African Americans. The stress of racism, coupled with such aforementioned issues of diet and vulnerability to certain race linked diseases and pathological conditions, make the study of speech and language disorders associated with stroke and other neurological impairments from a cultural perspective particularly important for African American and other culturally diverse populations.

Recommendation 2:

The NIDCD should commission research to obtain a more comprehensive data base on the effects of diet, race specific diseases and social consequences of racism on the prevalence of stroke and other neurological conditions that lead to speech and language disorders in African Americans.

Assessment Procedures and Instruments

Assessment, by its very nature, has built-in assumptions about the nature of communicative behavior being assessed in its normal state. Moreover, subsequent diagnoses based upon these assumptions ensue from assessment. In aphasia and kindred communication disorders, there are also presuppositions about normal, pre-morbid communicative behavior. In the past decade there has been considerable research on the nature of speech and language behavior and acquisition in normal African American children. The work of such individuals as Stockman, Vaughan Cooks, Taylor and Seamer typify this research. However, there has been a dearth of research on communicative behaviors in African American adults, particularly those in the more senior age groups that are vulnerable to stroke and other neurologically based communication disorders. While it is well known that communicative behavior changes with age, it is regrettable that we know so little of the affects of aging in healthy African Americans and other culturally diverse groups, and especially across the full spectrum of socioeconomic status and education. Many African American adults are proficient in more than one dialect of English, ranging from Black English Vernacular to Standard English. Many have extensive code switching capabilities. Few of these skills—and others similar to them— have been studied carefully in healthy African American adults. Such research is needed badly.

Further complicating the assessment and subsequent diagnosis of aphasia in African Americans is the problem of making assumptions about the premorbid communicative ability of the client. The assumption is often made that all, if not most, African Americans speak a variety of English that differs from standard English. This is true in many cases—but not in others. Thus, to presume a premorbid status of Black English Vernacular, for example, may in fact be discriminatory against some African American clients, but linguistically sensitive to others. On the other hand, there is the situation of the polydialectal aphasic, i.e., the aphasic who principally spoke standard English premorbidly, but who had a basilect (1st language system) that was Black English Vernacular that was no longer, or rarely, used. While we have considerable research on the polyglot aphasic, we do not have comparable work on the polydialectal aphasic. It may be assumed, however, that such aphasics have more linguistic vulnerability in their second dialect, in comparison with their first dialect.

Recommendation 3:

The NIDCD should support research on the nature of speech and language behavior in a cross-section of normal, healthy African American adults in order to establish baseline data to draw clinical conclusions about the nature of language sequelae to stroke and other neurological disorders.

Recommendation 4:

The NIDCD should support research on the nature of polydialectalism and code switching in normal healthy African Americans and determine the types of aphasic behaviors seen in such individuals following the onset of neurological impairment.

Treatment Issues

Treatment, as well as assessment and diagnosis, must be approached from a context of a social interactive situation in which both client (plus family) and therapist bring with them a set of social rules governing interactions. The social rules might include such categories of communicative behavior as appropriate topics of conversation, communication interactions, conversation postulates, etc. Not only must the therapist be informed of these rules, and adhere to them during treatment, but the therapist must build such considerations into management. In other words, the recovering African American aphasic should be taught how to communicate functionally competent in a variety situations, before a variety of audiences and for a variety of purposes. Furthermore, therapists must provide treatment in a context that will allow clients to communicate appropriately within the context of his or her community and family.

Recommendation 5:

NIDCD should support research on the normal interactive rules governing discourse within the context of a cross-section of the African American culture, adhere to them as much as possible and conduct treatment activities in such as a way as to facilitate a reasonably normal communicator following therapy.

Ways of Knowing

Perhaps the most important cultural consideration that must be made in conducting research on speech and language function in African Americans sequelae to stroke and neurological appairments involves the researcher's views on strategies for discovering truth. Historically, within the field of communicative disorders, high value has been placed on quantitative, or counting and measuring, ways of knowing. While these approaches to knowing have validity, so do other ways, most specifically various qualitative ways, including ethnographic approaches.

Qualitative studies of communication are rooted in ethnographic theory. Ethnography, a branch of anthropology, is the art and the science of describing a group or a culture from the perspective of phenomenology. The epistemological basis for the ethnographic paradigm embraces a multicultural perspective because it accepts multiple realities of truth. It presumes that individuals act on their individual perceptions and realities, and that these perceptions are influenced by the experiences and definitions of those experiences as defined by their culture.

Phenomenologically oriented studies are generally inductive in that they make few explicit assumptions about sets of relationships. In this model, the researcher approaches the research task with no a priori assumptions and is lead to sociocultural conclusions based upon empirical evidence which, as much as possible, is obtained and interpreted from the vantage point of the cultural group under study.

By contrast, the research paradigms commonly used in experimental psychology and frequently in communication sciences and disorders are commonly driven by positivistic theory. Unlike phenomenology, positivistic theory research paradigms assume the existence of an objective reality (often measurable), which leads the researcher, therefore, to pursue a deductive research approach based upon a priori assumptions about relationships.

Culture based orientations to research guide the formulation of research questions, types of data needed to answer these questions, selection of research tasks and instruments, methods of data analysis and interpretations of findings.

Recommendation 6:

NIDCD should promote culture based studies of aphasia and kindred disorders, including those based upon the theoretical constructs and analytical procedures subsumed under the ethnographic research paradigm, as well as those that focus upon qualitative ways of knowing.

Several years ago, the NIDCD sponsored a major symposium on communicative disorders in multicultural populations. There is evidence that the recommendations emanating from that symposium are already being implemented. I wish to congratulate the NIDCD for having convened today's very important symposium, and to urge it to be equally vigilant in implementing the recommendations that will inevitably emerge from the current symposium.

BILINGUALISM AND STROKE REHABILITATION: OLD QUESTIONS AND NEW DIRECTIONS

Arturo E. Hernandez, Ph.D.

The issue of bilingual aphasia is one of great fascination. In fact, it is the issue that got me interested in cognitive neuroscience in the first place. I was first interested in this topic when I began graduate school in 1991. Although much work has been done in the field of bilingual aphasia there is still a great deal of research to be done (Paradis, 1995). When I arrived at the University of California, San Diego, I realized that there was a lot we did not understand about bilingualism as phenomena itself. Hence, I set out to study the nature of bilingualism and the brain in general.

In the United States, according to the 1990 U.S. Census, about 20 percent (50 million) of the people in the country speak a language other than English. This number is much higher in states with large immigrant populations such as California where 37 percent of the population speaks a language other than English. In addition, the largest group are Spanish-speaking Americans. However, the nature of language processing in those who speak more than one language differs substantially from those who speak only one language (Grosjean, 1989; Harris, 1992). This carries heavy implications for the diagnosis and treatment of these individuals who have language disorders.

The importance of understanding the brain bases of bilingualism can be seen in a recent case study in the literature in *Brain and Language* that appeared in 1995. Gomez-Tortosa, Martin, Gaviria, Charbel and Ausman (1995) presented a case of a 22-year-old right-handed bilingual whose first language was Spanish. She lived for the first 10 years of her life in Bolivia, then came to the United States where she learned English and spent the next 12 years of her life. At the age of 19 she had a temporal parietal hematoma, which required surgery for its removal. After surgery the language impairment was more severe in the first language than in the second language. However, on closer inspection it is not clear that this was the case.

The experimenters administered the Boston Naming Test in both languages. In Spanish, half of the items were administered in Spanish before surgery and the full set was administered after surgery. In English, the full set of items were administered after surgery. The Boston Naming Test gets harder (items are lower in frequency) as one goes through the test. Thus, it is important to note that multiplying the score on half the items by two does not yield the same result as administering the entire test.

The data from these tests can be seen in Table 1. The results revealed a higher percent correct in English than in Spanish. Furthermore, there were a higher number of paraphasias in Spanish than in English. Finally, there were a number of pictures which the patient did not know in either language (omissions). Based on these findings Gomez-Tortosa et al., concluded that each language has different anatomical representations within the left perisylvian area.

TABLE 1.

VERBAL FLUENCY AND NAMING BEFORE AND AFTER TESTING

	BNT	Paraphasias	Omissions
Spanish Pre	21/30	No	Yes
Spanish Post	32/60	Yes	Yes
English Pre	N/A	No	Yes
English Post	44/60	No	Yes

Preliminary results in our lab, however, call into question Gomez-Tortosa et al.conclusions. In Table 2, are the results from the Boston Naming Test used with a group of college-age healthy controls. English controls correctly named 52 out of 60, bilinguals in English 47 out of 60, and bilinguals in Spanish 34 out of 60 on the Boston Naming Tests. If one looks at the number of pictures named correctly in English (44/60) and Spanish (32/60), it is clear that these scores fall well within normal range. In other words, healthy college-controls score the same as the patient that was presented! The pattern of English dominance can also be seen in the reaction times and accuracy for familiar pictures.

The results from our studies bring up two important points. First of all, it is important to do basic norming of tests for normal healthy controls before applying them to neurologically impaired populations. If Gomez-Tortosa had the data from college controls they would have concluded that the operation did not affect one language more than the other. In addition, no claims would have been made about neurological tissue being devoted to one language or the other. Second, the results from our study show that there is a difference between dominant language and native language. In fact, results from our lab have shown that many early Spanish-English bilinguals become dominant in English (their second language) by the time they reach college-age.

In addition to understanding the nature of language representation in isolation it is also important to extend the research on bilingualism to other performance measures. One way to do this is to examine other modes of communication. One thing that bilinguals will do is switch between languages in order to accommodate speakers who speak different languages. In some cases, bilinguals may actually have to switch on succession very rapidly. For example, a person who has to speak to a young cousin who only speaks English and to a grandmother who only speaks Spanish. In this situation, the person will have to translate on the fly back and forth, a task which is not easy to do. Despite these difficulties it is very common in the bilingual community. To explore this issue we designed a cued picture-naming paradigm in which a person hears a cue, the word "say," for English and the word "diga" for Spanish, at the same time that a picture is presented. The conditions were set up so that a person names pictures in one language or the other language or alternates between languages in a predictable manner.

The behavioral results which can be seen in Table 2 and Figure 1 show that errors were higher in the mixed condition compared to the blocked condition. Furthermore, reaction times were also slower when participants were in the mixed design. In addition, we also acquired neuroimaging data from this experiment. We asked people to name the pictures in their heads while we imaged their brain using functional magnetic resonance imaging which is correlated with blood flow in the brain and hence with neuronal activity. Results revealed no difference in activation for one language or the other (Hernandez, Martinez, Wong, Frank and Buxton, 1997). However, there was a significant increase in activation when participants had to alternate between languages when compared to naming in either of their languages.

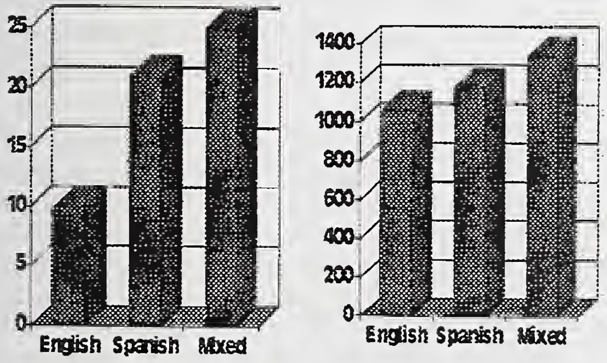
TABLE 2.

VERBAL FLUENCY AND NAMING FOR COLLEGE-AGED PARTICIPANTS

	BNT	Familiar Pictures	
	Accuracy	Accuracy	Speed
Monolingual English	52/60	81/90	964 ms
Bilingual English	47/60	81/90	1006 ms
Bilingual Spanish	34/60	66/90	1160 ms

FIGURE 1.

BILINGUAL CUED PICTURE NAMING: BEHAVIORAL RESULTS



In summary, I have made the point that basic research with bilinguals is important for a number of reasons. First, it is important to understand what the characteristics of a population are before making claims about the effects of brain injury in that population. In this case, performance of a group of healthy adult controls was identical to that observed in a patient with neurological damage. Second, the second language is not always the weaker language. Many immigrant groups show weaker performance in their first language. This is true for cases in which the second language is the one in which an individual is educated in. Third, performance measures such as reaction time must be used to understand how people access each language. By understanding how access occurs in real time we can bring to investigate how individuals use it in their everyday lives. Fourth, we need to understand what is the nature of brain activation in healthy bilinguals. By considering these four issues we can begin to put together a theory of how bilingual processing occurs.

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ENVIRONMENTAL AND CULTURAL INFLUENCES ON REHABILITATION AND RESEARCH

Danielle N. Ripich, Ph.D.

This afternoon I want to talk about two cross-cultural studies I have recently completed. We are currently in the fourth year of a five year project at the Alzheimer Disease Research Center at Case Western Reserve University in Cleveland, Ohio, entitled, "Effects of Communication Training on Caregivers of Persons with Alzheimer's Disease." The project, funded by the National Institutes of Health and National Institute on Aging, has a number of investigations within it. Today we'll discuss two. The first study I will present examines language in Alzheimer's disease (AD) and the second examines communications skills training for caregivers of persons with AD.

This research grew out of an earlier project—a longitudinal study of language loss in AD. We became aware of cultural differences in communication styles of caregivers who were bringing the persons with AD in for testing and of persons with AD. We observed differing patterns of communication. These differences led us to design a cross-cultural comparison study that looked at both the person with AD and at the caregiver.

Study #1: Comparison of African American and White Persons with AD on Language Measures

In the first study we compared African American and White persons with AD on language measures. That language declines across the course of AD is well documented, but there is no information on differences in language deterioration in African-American and White persons with AD. Yet the National Institutes of Health, Consensus Development Conference statement on Diagnosing the Dementias, specified that one of the highest research priorities should be the "evaluation of results obtained with current neuropsychological instruments in populations that differ in age, education, ethnic compositions, and social or cultural background" (National Institutes of Health, 1987). In fact, few studies have compared general cognitive abilities in persons with dementia from different ethnic groups. Screening scales for dementia yielded conflicting results for relative rates of cognitive impairment in African-American, Hispanic, and White groups, the differences attributed to varying sensitivities of the scales and to sociocultural bias (Gurland, Wilder, Cross, Teresi, and Barrett, 1992). The purpose of this study was to determine (a) if sociocultural group correlated with scores of African-American and White persons with AD on a number of language measures and (b) if any such relationship was influenced by education or level of cognitive functioning as measured by the Mini-Mental State Examination (MMSE; Folstein, Folstein, and McHugh, 1975).

Method

Subjects

Forty-three subjects (11 African-American [three men, eight women] and 32 White [11 men and 21 women]) were drawn from the Alzheimer Disease Research Center of University Hospitals of Cleveland and met NINCDS-ADRD criteria (McKhann, Drachman, Folstein, Katzman, Price, and Stadlan, 1984) for probable AD. All were native speakers of English, demonstrated adequate vision and hearing, and had no history of cerebral vascular accident, trauma, neoplasm, alcoholism, psychiatric, or metabolic disorder. These subjects were in the early to midstage of AD with MMSE scores ranging between 11 and 24.

Mean age for African-American subjects was 77.61 years (SD = 8.53) and for White subjects 77.56 years (SD = 7.26). Mean education level was 12.22 years (SD = 2.68) for African-Americans and 12.61 years (SD = 2.33) for Whites. Mean MMSE score was 16.18 (SD = 3.99) for African-Americans and 16.88 (SD = 3.36) for Whites.

Procedure

Language tests were administered by a certified speech-language pathologist or graduate students in speech-language pathology trained in the procedural methods. Measures of auditory comprehension were the Peabody Picture Vocabulary Test-Revised (PPVT-R; Dunn and Dunn, 1981) and the 16-item Shortened Token Test (Spellacy and Spreen, 1969). Measurements of oral expression were the Boston Naming Test (BNT; Kaplan, Goodglass, and Weintraub, 1983) and a modified 16-item Reporter's Test (DeRenzi and Ferrari, 1978). Subjects were also tested with a shortened version of the Rey Auditory Verbal Learning Test (RAVLT; Rey, 1958) to assess recall and recognition of an eight-item word list (two measures) and with selected items from the Test of Problem Solving (TOPS; Zachman, Jorgensen, Huisingh, and Barrett, 1984) to assess higher level cognitive skills in response to problem solving questions.

Data analysis

First, *t* tests were used to compare the ethnic groups on demographic characteristics. Next, separate analyses of variance (ANOVAs) were conducted with ethnicity as the independent variable and each of the seven language measures as a dependent variable. Then, to decrease variance associated with demographic characteristics, a series of one-way analyses of covariance (ANCOVAs) were performed on the language measures, with education and MMSE score as covariates. To account for multiple comparisons and protect against Type I errors, a Bonferroni-type correction was used with the ANCOVAs and alpha was set at .001.

Results

No significant group differences were found between African-Americans and Whites in terms of age ($t[41] = -.02$, $p > .10$), education ($t[41] = 1.09$, $p > .10$), MMSE score ($t[41] = .52$, $p > .10$), or gender distribution ($X^2[1, N = 43] = .003$, $p > .10$). Observed means and standard deviations for the language measures appear in Table 1, along with results of the ANOVAs and ANCOVAs. Before covariance,

Table 1. Comparison between African-American and White subjects on language measures

	Observed Mean (SD)			Adjusted Mean				
	African-American	White	ANOVA	African-American	White	ANOVA	Education	MMSE
Peabody Picture Vocabulary Test-Revised	104.27 (44.26)	129.94 (31.88)	F(1,40)=4.33*	109.19	125.02	F(1,40)=3.83	4.57**	4.19***
Shortened Token Test	69.00 (9.17)	66.53 (11.10)	F(1,40)=0.44	69.75	65.78	F(1,40)=1.56	.68	3.77***
Boston Naming Test	21.27 (14.71)	25.28 (15.07)	F(1,40)=0.59	22.97	23.58	F(1,40)=0.02	2.64*	4.31***
Modified Reporter's Test	43.82 (17.77)	47.94 (14.52)	F(1,39)=0.58	44.74	47.02	F(1,39)=0.23	-.08	3.63***
Rey Auditory Verbal Learning Test-Recall	0.82 (1.78)	0.97 (1.43)	F(1,37)=0.07	0.90	0.88	F(1,37)=0.00	.57	2.84**
Rey Auditory Verbal Learning Test-Recognition	5.70 (2.16)	6.66 (1.32)	F(1,36)=2.77	5.78	6.58	F(1,36)=1.90	.10	1.48
Test of Problem Solving (selected items)	15.64 (8.13)	12.97 (6.46)	F(1,40)=1.22	16.35	12.26	F(1,40)=5.26*	1.96	4.80***

Note: *t* values for the covariates Education and MMSE are displayed.
*p<.05, **p<.01, ***p<.001

there was a trend for White subjects to score higher than African-Americans on five of the seven language measures, although the only language measure which approached statistical significance was the PPVTR, $F(1,41) = 4.32$, $p < .05$. With education and MMSE score as covariates, however, the adjusted means for most variables were less discrepant between ethnic groups. MMSE score accounted for a significant portion of the variance in five of the seven measures; education in three of the measures. A group difference was shown on the TOPS, $F(1, 40) = 5.10$, $p < .05$, with African-Americans scoring higher than Whites. However, using the more stringent .001 alpha level, the difference was not significant.

Discussion

Linguistic data are useful in the identification of a dementia, in the differentiation of dementia, for monitoring dementia status over time, and for helping to determine approaches and goals in treatment of dementia. The challenge to identify socioculture free neuropsychological instruments is mandatory if clinicians are to correctly assess cognitive impairments in various cultural groups.

In this study demographic variables accounted for the differences between ethnic groups on the language tests. Level of cognitive functioning as measured by the MMSE and, to a lesser extent, education were strongly associated with current language performance in these subjects with early to midstage AD. Still, after accounting for these demographic factors, African-Americans tended to perform better on the TOPS, an expressive task that assesses the ability to explain inferences, determine causes, answer negative questions, determine solutions, and avoid problems. The TOPS thus measures pragmatic use of language on reasoning and judgement tasks, whereas the other six measures used in this study assess discrete linguistic abilities. African-American AD subjects in this sample tended to demonstrate better ability than White AD subjects to answer questions related to solving everyday functional problems. This may be due to a sociocultural difference. Sociocultural differences are diverse, extending to characteristics which include ethnicity, upbringing, lifestyle, language, education, diet, and numerous other factors. An additional difference may be problem solving styles, ability to perceive problems, draw from experience and consider and choose from various solutions. The African-American sociocultural experience may provide the person with AD with more competency in dealing with problem solving situations.

The possibility that language tests are differentially sensitive in ethnic groups cannot, however, be ruled out entirely by the results of this study. Certain language measures did show trends toward group differences. This may occur for a number of reasons. Groups may differ in language abilities, that the measures are biased, or that both these and other factors affect outcomes in language tests. The small sample size here limited the power of the analysis (power ranged from .10 to .36 for the language measure analyses), and a larger sample, particularly more African-Americans would have improved the power of the study. Clearly, the results of this study should be considered preliminary. Additional studies using known non-biased measures with larger numbers of African-American and Whites should provide additional analysis of ethnic differences and similarities in AD subjects.

Study # 2: Effects of a Training Program on African-American and White Caregivers

In the caregiver study we examined the effects of a communication training program on the two groups. As Dr. Payne told us this morning, older African-American individuals currently represent the largest ethnic subgroup in the United States and account for 8 percent of the people over 65 years of age. Because life expectancy is increasing for members of minority groups, this group will increase into the twenty-first century making up 10 percent of elderly Americans by the year 2050 (U.S. Bureau of the Census, 1993). It is assumed that dementias occur in African-Americans in at least the same proportions as the general population (Mortimer and Hutton, 1985; Valle, 1989). Therefore, the numbers of African-Americans with dementia is expected to increase. Although the body of literature which studies the patterns of caregiving in minorities is growing, no study to date has explored the effects of an intervention program for minority caregivers of persons with AD. Ethnicity group is an importance factor in caregiving with ethnic variations in attitudes, norms, practices, and expectations affecting both the caregiver and care recipient in the nature of caregiving and preferences for caregiving (Lawton, Rajagopal, Brody, and Kleban, 1992; Magnum, Garcia, Kosberg, Mullins, and Barresi, 1994; Morycz, Malloy, Bozich, and Martz, 1987). Consequently, behavioral intervention programs may need to be tailored to meet the needs of particular ethnic groups.

Ethnic Differences in African-American and White Caregivers of Persons with Dementia

African-Americans have more powerful kinship constructs and rely less on formal caregiving than White caregivers (Cox and Monk, 1990; Devore, 1983; Gelfand, 1982; Hatch, 1991; Segall and Wykle, 1989; Wykle and Segall, 1991) and are less likely to institutionalize family members with AD compared to White caregivers (American Association of Retired Persons, 1986; Green and Ondrich, 1990; Morycz, et al., 1987). Furthermore, African American caregivers report less stress and burden than White caregivers (Hinrichsen and Ramirez, 1992; Lawton, et al., 1992), greater satisfaction in caregiving (Lawton, et al., 1992), and less depression than White caregivers (Haley et al., 1995). As a coping strategy, more African-American caregivers used prayer and religious faith as a personal support (Crawley, 1987; Haber, 1984; Segall and Wykle, 1989; Taylor and Chatters, 1986; Wood and Parham, 1990), while White caregivers showed more diverse coping strategies (Wykle and Segall, 1991).

Communication and AD

Communication breakdown in persons with AD is consistently listed among the top stressors in family caregiver surveys of stress as strain and burden (Hirschfield, 1983; Kinney and Stephens, 1989; Levine et al., 1983; Rabins, 1982; Zarit, 1982). The goal of quality caregiving should clearly be to prolong and promote communication between persons with AD and primary caregivers for as long as possible and at the most interactive level (Clark, 1995). Although the literature is replete with suggestions for counseling, coping, and social support for caregivers, to date, no systematic, comprehensive training program for improving communication skills for caregivers has been developed and evaluated.

As the aging population increases, the need for interventions to help families care for elderly members becomes more urgent. How specific interventions impact differing ethnic groups has yet to be examined. The purpose of the present study was to investigate the following questions: (a) Does communication training for family caregivers of persons have an effect on reports of affect, health status, burden, knowledge about communication and AD, and communication satisfaction? (b) Do the effects of communication training differ between African-American and White family caregivers?

Method

Subjects and Procedure

Subjects. Twenty-eight (eight African-American and 20 White) caregivers of family members with probable AD recruited from the Alzheimer Disease Research Center of University Hospitals of Cleveland participated in the investigation. Ninety-three percent of the African-American caregivers were female, compared to 55 percent of White caregivers. Mean age of African-American caregivers was 57.1 years (*SD*=10.6) and 63.7 (*SD*=13.8) for White caregivers. Mean years of formal education for African-American caregivers was 13.3 years (*SD*=2.1) and 14.2 years (*SD*=2.6) for White caregivers. Information on socioeconomic status (SES) was gathered using scores based on the 1980 census occupational classificatory scheme (Stevens and Cho, 1985). African-American caregivers had a rating of 43.8 (*SD*=21.5) and White caregivers 50.8 (*SD*=18.0). Thirteen percent of African-Americans had a spousal relationship with their family member with AD (care receiver) compared to 60 percent for White caregivers.

Communication training material. Caregivers were asked to participate in eight hours of training over four weekly sessions in groups of eight to 10 persons. The material used for training was the *Alzheimer's Disease Communication Guide: the FOCUSED Program for Caregivers* (Ripich, 1996), a comprehensive, systematic program of instruction designed to provide information about AD and communication, correct misconceptions about how to communicate with persons with AD, and offer techniques to enhance communication potential for family members with AD (see Appendix A and Appendix B). Training procedures and materials included discussion questions, videotaped vignettes, role-play activities for practicing specific strategies, and handouts to caregivers.

Measures

Overview. Self-completed questionnaires, collected pre- and post- training, measured subjective well-being, levels of depression, and subjective health. Stress and burden levels were examined by measuring daily hassles related to caregiving. In addition, caregivers' factual knowledge about Alzheimer's disease and communication was assessed. Finally, a question about the caregiver's attitude toward communicating with the family member with AD measured communication satisfaction. Measures were:

Positive and negative affect -five indicators of positive affect (PA) and five of negative affect (NA) using a modified version of the Positive and Negative Affect Scale (PANAS; Kercher, 1992; Watson, Clark and Tellegen, 1988).

Depression-a 12-item modification of the Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977).

Health status- a three-question survey of perception of health designed as a five point rating scale.

Hassles-the Caregiver Hassles Scale (Kinney and Stephens, 1989), 42 items based on a transactional perspective in which stress is conceptualized as hassles, or minor irritations, of daily living (Lazarus and Folkman, 1984).

Knowledge of AD and communication-a 10-item Knowledge Assessment (true/false and multiple choice format) developed by the authors to measure knowledge of AD (such as, characteristics and pathology of AD) and communication in AD (such as, language components, language deterioration in AD, and communication strategies).

Communication satisfaction-an attitude question relating to satisfaction in communicating with the family member with AD also developed by the authors.

Data analysis. Seven 2 (ethnicity: African-American vs. White) x 2 (time: pre-training vs. post-training) between-subjects repeated measures analysis of variance (ANOVA) were performed to examine the effect of communication training on the seven measures included in the study (i.e., PA, NA, CES-D, Hassles, Health status, Knowledge assessment, and Communication satisfaction).

Results

T-tests showed no significant differences for age, education, socioeconomic status, or gender of caregivers. However, the examination of spousal relationship between the two groups revealed that significantly more White caregivers were spouses compared to African-American caregivers, $X^2(1,N)=5.18$, $p<.05$. Due to this finding, spousal relationship was added as a covariate in the subsequent ANOVA analyses.

Table 2 presents the means and standard deviations for the seven dependent variables in the study at both pre- and post- testing. African-American caregivers had a higher overall score on the PA scale of the PANAS compared to White caregivers. Significant main effects were also found for the Knowledge assessment and Communication satisfaction measures, with scores increasing for both groups following training. Finally, a significant interaction effect was found for the Hassles Scale with the average score of African-American caregivers decreasing post-training compared to pre-training, while White caregivers had no change in their average score.

Discussion

It is critical to consider ethnicity and the reticent nature of African-Americans to fully discuss their beliefs and feelings when considering responses to questionnaires. African-American caregivers have difficulty seeing caregiving of a family member or a non-family member as a burden. Caregiving is an accepted responsibility

Table 2. Mean (standard deviations) for African-American and White caregivers on stress and burden measures and F values for repeated measures ANOVA

	Pre-testing		Post-testing		Group Effect	Ethnicity Effect	Interaction
Measure	White (N=20)	African-American (N=8)	White (N=20)	African-American (N=8)	*F* value	*F* value	*F* value
PANAS							
Positive Affect	15.37 (3.7)	19.38 (4.5)	16.17 (3.1)	18.75 (4.2)	.04	5.33*	1.47
Negative Affect	10.79 (4.4)	10.50 (3.6)	11.06 (4.7)	9.75 (1.5)	1.05	.51	1.22
Caregiver Hassles Scale	26.20 (12.0)	65.00 (14.1)	35.31 (18.5)	41.00 (18.9)	4.05	3.71	12.45**
Knowledge Assessment	7.00 (2.5)	7.71 (1.9)	10.78 (1.2)	11.00 (1.0)	41.44***	.40	1.08
Attitude Questionnaire	1.32 (.48)	1.00 (0)	1.39 (.61)	1.38 (.74)	5.56*	.01	1.64
Subjective Overall Physical Health	12.06 (2.5)	12.40 (2.1)	12.00 (2.4)	12.00 (2.8)	.11	.02	.21
CES-D	25.20 (8.0)	22.00 (5.5)	25.83 (9.3)	22.13 (4.9)	.05	2.13	.01

Note: *p<.05, **p<.01, ***p<.001

and shameful when thought of in any other way (e.g. a burden). Thus, caregivers may answer what they think is expected, particularly when being positive about their caregiving tasks. They may require substantial time to establish trust and rapport with the interviewer so that they answer questions more accurately. Caution should be taken when examining data that shows marked differences between African-American and White individuals in attitudes toward caregiving of persons with AD.

The results of this study clearly demonstrate that African-American and White caregivers benefit from additional knowledge and skills that make relating to the care recipient easier. Training provides caregivers with skills that increase their sense of competency in caring for the family member with AD. Findings suggest that providing a way for caregivers and persons with AD to continue to communicate in a meaningful way is gratifying. Communicating is a two-way process that all human beings expect and rely on for contact. Increasing caregiver understanding of the best way to communicate and what they can expect relieves the caregiver's frustration and sense of helplessness regardless of ethnic group.

SUMMARY

In summary these studies suggest a greater flexibility in the use of functional language by African-Americans both for persons with AD and for their caregivers. It seems this points to a need to better understand the influences of the cultural milieu from communication as well as the influence of the neurological substrates underlying the organization of language across cultural groups.

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APPENDIX A

FOCUSED Communication Training Content

Module 1: Alzheimer's Disease (AD) and the associated communication and language decline.

Characteristics and pathology of AD

Diagnosis of AD

Communication processes and components (phonology, syntax, semantics and pragmatics)

How language in aphasia differs from language in AD

Module 2: Differences between normal forgetting in aging and AD. Depression in aging.

Memory processes

Normal changes in memory with aging and how it differs in AD

Symptoms of depression vs. Symptoms of AD

Problems in abstraction and judgment in persons with AD

Effects of depression on the person with AD's already decreasing ability to communicate

Module 3: Importance of communication in AD. Specific techniques to promote communicative effectiveness for as long as possible.

Importance of self-esteem

Basic communication skills

Seven FOCUSED strategies to promote interactive communication (Face to face, Orient to topic, Continue topic, Unstick communication blocks, Structure questions, Exchange communication, Direct, short sentences)

Module 4: Implementing the FOCUSED Program with persons at each stage of AD.

Three main stages of language changes in AD

Assessment and recognition of stages

Approach and goals for each stage using the FOCUSED strategies

Note: Adapted from Ripich, DN. *Alzheimer's Disease Communication Guide: The FOCUSED Program for Caregivers.* San Antonio: The Psychological Corporation, 1996.

APPENDIX B

FOCUSED Communication Strategies

Following are the strategies associated with the key words of the FOCUSED acronym.

F = Face

Face the person with AD, face-to-face

Call his or her name

Touch the person

Gain and maintain eye contact

O = Orient

Orient the person with AD to the topic by repeating key words several times

Repeat and rephrase sentences

Use nouns and specific names

C = Continue

Continue the same topic of conversation for as long as possible

Restate the topic throughout the conversation

Indicate to the person with AD that you are introducing a new topic

U = Unstick

Help the person with AD become "unstuck" when he or she uses a word incorrectly by suggesting the intended word

Repeat the sentence the person said using the correct word

Ask, "Do you mean...?"

S = Structured

Structure your questions so that the person with AD will be able to recognize and repeat a repeat

Provide two simple choices at a time

Use yes/no questions

E = Exchange

Keep up the normal exchange of ideas we use in everyday conversation

Keep conversations going with comments such as, "Oh, how nice," or "That's great"

Do not ask "test" questions

Give the person with AD clues as to how to answer your questions

D = Direct

Keep sentences short, simple, and direct

Put the subject of the sentences first

Use and repeat nouns (names of persons or things) rather than pronouns (he, she, it, their, etc.)

Use hand signals, pictures, and facial expressions.

ENVIRONMENTAL AND CULTURAL INFLUENCES ON REHABILITATION AND RESEARCH

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Recruitment of subjects for clinical trials or research studies is often a very time-consuming, expensive, and arduous task. Although an investigator may employ intensive efforts to recruit appropriate subjects, it is highly likely that only a small number of respondents will ultimately meet the selection criteria (Ballard, Nash, Raiford, & Harrell, 1993).

Recruitment of African-Americans and other minority groups in this country is generally even more difficult. African-Americans often are underrepresented in clinical trials and research protocols despite the high prevalence of stroke and hypertension within the population (Ballard, et al., 1993). Many speech-language pathologists and related professionals recognize the need to become more knowledgeable about communication disorders and stroke in African-Americans and other culturally and linguistically diverse populations. The clinical questions about this topic can only be answered if sufficient numbers of participants are evaluated. However, there are many factors that must be considered when developing effective recruitment strategies for participants from multicultural populations in research projects. The potential obstacles should be identified and mechanisms should be established to minimize the obstacles such that appropriate numbers of individuals can be recruited into clinical-research studies.

Therefore, the purpose of this segment of the program is to present some of the environmental and/or cultural factors that may influence research participation by individuals from diverse cultural and linguistic backgrounds. Potential barriers to research participation will be identified; mechanisms for eliminating or minimizing these barriers will be reviewed; and examples of effective outreach efforts will be presented.

It is important to note that deterrents to successful recruitment of African-Americans and other ethnic minorities may differ depending on a number of variables, such as the cultural differences within the ethnic group, the geographical region, the age and gender, and the specific nuances of the particular study. Factors that may influence participation in one study may not be significant in another study (Ballard, et al., 1993). However, it is essential that investigators be aware of as many of the possible barriers that could exist and how the barriers can be minimized or eliminated in order to better develop and implement their recruitment efforts.

Perhaps one of the most significant factors influencing research participation by African-Americans during this century is the Tuskegee Syphilis Study performed between 1932 and

1972. This medical experiment is likely to be the single most incident in the history of the United States (Public Health Service) to have an impact on the trust and confidence of African-American people, particularly the elderly, with regard to participating in any form of biomedical or behavioral research. Establishing an environment of trust, providing a purpose that is clearly understood and relevant, and providing assurances of highly ethical practices are, at minimum, essential ingredients to having a successful recruitment and retention effort.

Another factor that will influence participation of African-Americans and other ethnic minorities in research studies is the perception that there is a disconnection between the participant and the researcher. It is essential that investigators have thorough knowledge of the sociocultural aspects of the ethnic community in which they are trying to recruit (Ballard, et al., 1993). The perception (or reality) that an investigator lacks understanding of the participants cultural background may be reflected in a number of ways, such as the composition of the research team, the cultural attitude of the participant (i.e., beliefs and views concerning health, rehabilitation and illness), the verbal and nonverbal interactions between the participant and the investigator, the therapeutic incentive or relevance of the study to the participant, and the selection and manner of presentation of research tools or materials during the study (Nellum-Davis, 1993; Wallace, 1993).

Often, individuals from diverse cultural and ethnic backgrounds are less willing to participate in studies in which they share no commonalties with the research team members; i.e., the principal investigator, the graduate research assistant, or the numerous consultants that may be involved in the study. It is important to consider the subjects that you are trying to recruit in terms of their cultural, ethnic and linguistic background, their gender, etc., and make attempts to expand the existing scope of collaborations such that a research team can be assembled that reflects not only specific areas of scientific expertise, but also reflects the cultural and ethnic diversity of the subject pool (Nellum-Davis, 1993). Secondly, it is important that we as clinical-researchers achieve cultural or ethnic competence; that is, that we take the time to increase our understanding of, and sensitivity to the diverse cultural and ethnic groups that we are trying to include in our studies. For example, in many African-American families care is traditionally provided at home and outside assistance is generally not sought (Nellum-Davis, 1993; Wallace, 1993). Families may be unwilling to participate because of a lack of awareness of possible rehabilitation or research alternatives, or because they simply prefer to retain their traditional cultural attitudes and behaviors.

The accessibility of the study site to certain segments of the community may present another barrier to recruitment (Ballard et al., 1993). This issue relates to the perceived or real notion that some members of diverse cultural or ethnic minority groups have that the clinical-research environment is reserved for ethnic groups other than their own. These attitudes may be reinforced by such factors as facility location, payment policies, diversity of the professional staff, etc. Consideration should be given to selecting a site for research studies that is culturally-neutral; that is, one that does not violate the intraethnic variability of social organization (Ballard et al., 1993).

Investigators need to carefully consider what benefit participation in the study provides each individual being recruited; and how the individual may view the meaningfulness of their participation in that study. These questions should be considered from a practical sense, and in the context of how the potential participant is currently functioning; that is, the participant merely struggling to maintain a level of existence within marginal economic and educational boundaries (Ballard, et al., 1993).

Another barrier to successful recruitment is the lack of education and information about the disease or condition being studied (Ballard, et al., 1993). At times individuals who possess a lower level of formal education and literacy may have different levels of understanding about a particular disease or condition (such as stroke), such that they are not likely to seek medical assistance or be willing to participate in a study to investigate that condition. Therefore, it is important that one step in the recruitment process include the provision of specific information about stroke and communication disorders; before the issue of research participation is presented. Repeat visits or personal contacts with potential participants and family members (e.g., letters, telephone calls, home visits) should be included in the outreach plan. This form of community education may be important for the potential subject as well as the circle of primary care physicians and related health professionals, and family members and caregivers (Ballard, et al., 1993).

Economic issues have also been reported as possible factors that influence the recruitment and retention of African-Americans in research studies (Ballard, et al., 1993; Wallace, 1993). The development of effective outreach programs may be hampered when there is inadequate financial support. Investigators should consider the direct or indirect costs that may be associated with a research study, for example, transportation-related expenses. These factors may be addressed by providing transportation at no cost, by providing a stipend to cover the cost of transportation expenses, or by traveling to the site of the participant (Wallace, 1993).

Transportation, parking accessibility, and time consumption may also influence participation of some African-Americans in research studies. The potential participant may heavily rely on public transportation, possibly incurring delays and multiple transfers; there may be safety issues surrounding the participant leaving or returning home at certain times of the day; it may be physically challenging to actually transport the participant to the study site; or there may be inadequate parking facilities for individuals with private vehicles (Wallace,1993). Consideration must be given to what the participant and/or the caregiver may view as possible inconveniences, and how time-consuming and troublesome it is for them to deal with those inconveniences in order to participate in the study.

In summary, it is crucial that investigators have a familiarity with, and an understanding of, the ethnic and cultural history, behavior, attitudes and traditions of the individuals they are trying to recruit into research studies. Generally, within most African-American communities, there is little or no problem with retention within research studies if the barriers to recruitment are addressed successfully. Educational brochures (considering educational level and language preferences) may be developed as a part of the outreach plan in order to increase the community awareness of stroke, as well as an understanding of the specific research program. Brochures could be distributed as part of a community education effort to senior centers, churches, nursing homes, local stroke clubs, civic organizations, and other sites where African-Americans are likely to frequent.

Possible mechanisms for eliminating or minimizing the potential barriers investigators face when recruiting African-Americans into research studies are: collaborating with individuals who are of a similar cultural or ethnic background (or who have knowledge of the cultural group being recruited); establishing a referral network; providing information about community resources for caregivers and participants; highlighting direct benefits and incentives; offering reimbursements for transportation expenses; and minimizing perceived or actual accessibility issues, transportation difficulties, and personal expenses incurred by the participant or the family.

Numerous barriers to understanding stroke and communication disorders in African-Americans and other ethnic minorities may exist; I have highlighted only a few. However, the prospect of more effective recruitment and outreach efforts is encouraging with greater flexibility to study design, enthusiasm towards embracing cultural differences, more trusting and ethically sound environments, and clear explanations of research objectives.

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RACE-COMPARATIVE VERSUS RACE-HOMOGENEOUS PARADIGMS IN NEUROPSYCHOLOGICAL STUDIES OF AFRICAN AMERICAN STROKE PATIENTS

Alfonso L. Campbell, Jr., Ph.D.

Excellent models of brain-behavior functions have been derived from neuropsychological studies of stroke patients. Until recently, however, very few studies in human neuropsychology examined higher cortical functions in African Americans. Neuropsychological studies of African American patients with stroke are still quite rare (Brown et al., 1991; Campbell et al., 1991). The lack of interest shown in issues that relate to brain-behavior functions in African Americans and other ethnic minorities is especially noteworthy in light of a growing literature which shows that ethnicity and culture serve as important determinants of performance on measures of higher brain function. In clinical and experimental neuropsychology, the currently accepted model of higher cortical functions is derived primarily from the studies of Euro-Americans. This model is singularly lacking in its ability to conceptualize neuropsychological functioning beyond the narrow parameters established by the behavior of Euro-Americans.

This presentation will focus on the merits of race-comparative and race-homogeneous paradigms in work with African American stroke patients in particular and brain-injured African Americans in general. First, let us consider the work of Andrew Brown. As a student in our graduate program, he conducted a master's thesis project which looked at the neuropsychological effects of acute lateralized cerebrovascular lesions in an African American population (Brown et al., 1991). In that study, 37 patients, including 15 males and 22 females, were participants. These patients (mean age= 56, mean years of education =9.5 years) were selected from a population admitted to the Neurology Service at Howard University Hospital with acute cerebrovascular lesions. Twenty-two patients had sustained a right hemisphere stroke and fifteen patients had cerebrovascular lesions in the left hemisphere. Persons were eligible to participate if they were right-handed with no previous history of a psychiatric disorder, brain damage, and alcohol or other substance abuse. Each patient was given the Michigan Neuropsychological Battery (MNB), which is comprised of objective standardized measures of a broad range of language, verbal and nonverbal reasoning, auditory and visual memory functions, and some somatosensory and motor skills. While only one of the measures of higher cortical functions in the MNB systematically differentiated right and left brain-injured patents, several important findings emerged.

The overwhelming majority of studies have noted that patients with left hemisphere lesions

Table 1. Mean MNB Scores of Patients in Group LBD and RBD

Neuropsychological Measures	RBD (n = 22)	LBD (n = 15)
VIQ	80.70	72.50
PIQ	70.90	72.40
FSIQ	74.90	71.70
VOT	15.10	13.10
RAVENS	16.10	18.40
BVRT(A)	2.73	2.50
BVRT(C)	5.41	5.22
SDMT(W)	12.90	11.20
SDMT(O)	16.40	15.40
MJS	25.20	21.00
PPR60	14.60	8.60 *
PPL60	5.41	18.90 *
SDSSL	11.40	15.00
SDSSR	14.20	11.90
BVRTMC(A)	4.70	7.10 *
BVRTMC(C)	7.00	9.44

*$p < .05$

VIQ=Verbal IQ Score

PIQ=Performance IQ Score

FSIQ=Full-Scale IQ Score

VOT=Hooper Visual Organization Test

RAVENS=Ravens Coloured Progressive Matrices Test

BVRT(A)=Visual Retention Test (Administration A)

BVRT(C)=Visual Retention Test (Administration C)

SDMT(W)=Symbol Digit Modalities Test (Written)

SDMT(O)=Symbol Digit Modalities Test(Oral)

MUS=Memory for Unrelated Sentences

PPR60=Purdue Pegboard (right hand/60 seconds)

PPL60=Purdue Pegboard (left hand/60 seconds)

SDSSL=Single and Double Simultaneous Stimulation Test (left side)

SDSSR=Single and Double Simultaneous Stimulation Test (right side)

BVRTMC (A)=Visual Retention Test: Multiple Choice Form (Administration C)

earn higher Wechsler PIQs (Performance IQ Scores) than VIQs (Verbal IQ Scores). On the other hand, patients with right hemisphere damage earn higher VIQs than PIQs. Consistent with the literature, Brown et al. (1991) showed that patients with right hemisphere damage earned a lower mean PIQ than VIQ score. But, in contrast to the majority of other studies in the area of research, the mean PIQ and VIQ scores of patients in Group LBD were virtually identical. The absence of a systematic difference in VIQ and PIQ scores of left hemisphere patients may be accounted for in several ways. First, the functional overlap of Verbal and Performance subtests noted by other researchers may have contributed to the unusual pattern of WAIS-R performance among patients with left hemisphere lesions in our study. Alternatively, the failure to find a significantly higher PIQ and VIQ score among patients with left hemisphere lesions may be related to the presence of subtle disease and/or other functional abnormalities in the presumed healthy right hemisphere.

There is an MRI study which shows that among 42 volunteers free of cerebrovascular symptoms, white matter lesions were present in 95 percent of the participants with two or more risk factors and 32 percent of the volunteers with fewer than two risk factors (Lechner et al., 1988). Most of these lesions were situated in watershed areas, which are known to be subject to chronically reduced perfusion rates in cerebrovascular disorders. In another study a different group of researchers reported significant declines in regional cerebral blood flow (RCBF) in both cerebral hemispheres of patients with the multiple risk factors (Shaw et al., 1984). These reduced RCBF values were slightly lower in homologous regions of the right hemisphere, with accelerated declines in prefrontal, parietal and inferior temporal regions of the brain. Together these findings suggest that widespread cerebral dysfunction is more likely to be present among persons with multiple risk factors for stroke and that right hemisphere functions are more vulnerable to risk factors such as 1) arterial hypertension, 2) diabetes mellitus, 3) hypercholesterolemia 4) smoking 5) heart disease and 6) kidney disease. Since risk factors for stroke are independently related to neuropsychological outcome, neurobehavioral correlates of stroke can be fully understood without taking into account these comorbid processes. Questions concerning the possible relationship between these risk factors and neuropsychological test have great theoretical and practical importance and should be examined in future studies.

Brown et al., (1991) also reported that the IQs of brain- injured African Americans were lower than the WAIS-R IQs of brain-injured Euro-Americans reported in other studies. It would be highly misleading, however, to conclude that brain-injured African Americans showed greater neuropsychological impairments than brain-injured Euro-American. Apparently those biases which contribute to the differences between African American and Euro-Americans on IQ tests prior to brain injury appear to have the same impact on these scores postictally.

When we compared the IQs in Brown et al., (1991) with the IQs of a comparable group of normal African American controls participating in a cross-validation study, the magnitude of the difference was the same as that reported in studies of Euro-Americans patients with normal intact brain functions and those with lateralized lesions. In contrast to the majority of studies in this area of research, the VIQ and PIQ scores of patients with left hemisphere stroke were virtually identical. It is not clear what these findings mean in terms of the cerebral organization of the cognitive processes tapped by the WAIS-R IQ test, but the disparate pattern of IQ scores observed in our sample of patients with left and right hemisphere damage suggests that relative to Euro-Americans Brown's sample of African American stroke patients brought a different information processing style to bear on the stimulus information presented in WAIS-R subtests than did brain-injured Euro-Americans. This difference in processing style only became apparent following damage to the brain.

Now let's consider a study in which we employed the race-comparative paradigm to look at the predictive validity of several neuropsychological measures. The values used to make these diagnostic decisions were conventional neuropsychological cutoff scores which appeared in published manuals or published validation studies involving these neuropsychological instruments. Ford-Booker et al. (1993) examined the predictive accuracy of several tests of a modified version of the Michigan Neuropsychological Batter (MNB) in a group of normal African American adults. This population had a mean age of 56 years and mean education of 9.5 years. They noted that while the number of controls misidentified as brain-impaired (i.e., false positives) varied across tests in general misclassification rates were very high (range 27 percent to 84 percent). Clearly these findings show that the impact of ethnicity/culture on neuropsychological test performance should be taken into account.

Recently, Miller, Heaton, Kirkson & Grant (1997), a group of researchers at the University of California at San Diego (UCSD), have been looking at the predictive accuracy of neuropsychological test results with African American and Euro-American males who were HIV+. Analyses showed that 71 percent of African Americans were rated impaired, as compared to 38 percent of the Euro-American group. The application of neuropsychological norms developed for African Americans reduced the percent of HIV+ Americans rated as impaired to 44 percent. Clearly, these preliminary data raise serious questions about the utility of neuropsychological test norms with groups dissimilar in sociocultural background to the normative population. They also underscore the importance of comparing individuals to persons from the same background.

These findings hold several implications for neuropsychological research and service delivery involving African Americans and other ethnic minority groups. There is a general consensus among most experienced clinical neuropsychologists that, in the context of a comprehensive neuropsychological test battery, the information that a single instrument contributes to neuropsychological assessment can be quite meaningful (Lezak, 1995). There is also agreement that high misclassification rates for single neuropsychological tests preclude their use as indices of the brain's functional integrity. There are, however, several valid methods that can be used for a more comprehensive interpretation of higher cortical functioning (Lezak, 1996; Reitan, 1986). Because these multiple inferential approaches may also be subject to the influence of sociocultural factors, it is important that the relationship between these methods of neuropsychological test interpretation and ethnicity/culture be explored.

Researchers have also noted that, in addition to age, gender, education, socioeconomic status (SES) may account for an important amount of the variance in neuropsychological test performance. Certainly this factor needs to be explored in greater detail in neuropsychological studies. Inasmuch as demographic factors impact on neuropsychological performances, there is a critical need to develop demographically sensitive norms for these measures (Bornstein, 1990). But African Americans are not a monolithic group, for social and demographic factors also provide a distinct basis of differentiation which influence their lives. Therefore, researchers and clinicians should also take these factors into account when evaluating the neuropsychological performances of African Americans and other ethnic minority groups.

Numerous researchers have established that human functioning cannot be separated from the cultural and immediate social; context in which the behavior develops (Miller-Jones, 1989; Vygosky, 1978). Relatedly, Boykin (1991) and Miller-Jones, (1989) have noted that standard psychological test situations are context-specific environments that are culturally informed. These contexts exert influence on both the accessibility as well as the deployment of cognitive processes in specific test situations (Miller-Jones, 1989). Since the development of cognitive processes occurs in culturally organized activities, it is obvious that these processes should be measured in similar cultural contexts. The failure to structure the measurement of these processes in a meaningful cultural context can lead to an incomplete and distorted view of these processes as well as misinterpretations of performance data.

Recently, in another HIV study, Jennifer Manly and her colleagues at UCSD noted that 20 White HIV+ patients earned significantly higher scores on neuropsychological tests than HIV+ African Americans matched on age, education, gender and disease stage. When the score earned by each participant on the African American acculturation scale was used as a covariate, ethnic group differences disappeared. This rather innovative approach showed that by accounting for within-group differences the neurodiagnostic accuracy of selected neuropsychological tests improve (Manly, Miller, Heaton, Grant, & HNRC Group, 1997).

During this presentation, I have highlighted some of the more salient neuropsychological issues that need to be considered in work with African American stroke patients. Foremost among the issues that I have reviewed is the tendency of neuropsychological tests to overdiagnose organic impairment in neurologically intact African Americans and to exaggerate the level of neuropsychological impairment among those with stroke. As a remedy for this situation, I submit that a "race-homogeneous" approach serve as the primary model of inquiry when assessing and interpreting the neuropsychological test performances of African Americans and other ethnic minorities. This approach involves comparing the neuropsychological test performance of demographically matched brain-injured and normal controls from the same racial or ethnic group. It may aid in separating out the confounding influence of culturally-linked variations attendant to the race-comparative paradigm. Moreover, the race homogeneous approach provides a context in which extant and new theoretical conceptions of brain-behavior functions derived from research with one ethnic group can be examined for their generalizability to other ethnic and racial groups.

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APHASIA EXAMINATIONS AND MINORITY POPULATIONS

Rita S. Berndt, Ph.D.

The assessment instruments that are typically use to evaluate adult aphasic patients differ somewhat in their potential for cultural bias when compared both to standardized tests used for neuropsychological assessment and to language batteries used to chart normal and pathological language and speech development. One important difference is that aphasia tests are typically not designed to locate an individual's performance relative to a normal distribution; rather, most test items included in aphasia tests are presumed to be well within the range of any language user. For this reason, aphasia tests are usually not "standardized" with a normal population, instead, a patient's performance is compared against the performance of a sample of other aphasic patients. Reports of such sampling with aphasic patients most often fail to include information about the race or ethnicity of the subjects. Is it possible to estimate the degree of cultural bias found in aphasia tests and to predict the impact of such bias on patients' management? There are two independent factors—severity of aphasia and the premorbid education level of the patient—that must be considered when assessing the potential impact of cultural differences on the test's ability to produce an accurate picture of patient's language status.

In cases of severe impairment, the goal of the aphasia test is to evaluate very rudimentary aspects of human communication. Such tests typically allow the patient to use any available means for communicating basic needs and desires. If the severely impaired patient can be made to feel that the assessment setting is a nonthreatening one, there is little danger that the tests themselves would produce different outcomes based on the cultural background of the patient. The situation is much different at the other end of the severity continuum. Mildly impaired patients are assumed to be approaching normal function; thus, it is imperative that assessments of progress and recovery accurately target relevant aspects of the patient's premorbid functioning. The educational level of the patient is especially critical in the assessment of a mild aphasia, where the degree of literacy and range of life experiences become potent predictors of an individual's facility with knowledge and vocabulary from outside his or her cultural milieu. At the "mild" end of the continuum, aphasia test results might affect important management decisions, such as whether or not the patient can return to work. To the extent possible, it is clear that tests used for such purposes should be targeted at specific communicative requirements for the target situation.

One of the primary functions of aphasia tests in contemporary practice is the documentation of continued improvement for insurance purposes. Many carriers now require that such documentation be based on a "functional" assessment of the most basic communicative functions. This situation provides an opportunity to design new instruments that can be adapted to the cultural context that is appropriate for an individual patient. Several examples of such tests are currently available. In light of the fact that the development of new aphasia tests does not require extensive standardization, new approaches to culturally unbiased functional assessments can be developed to span the range of impairment severity and of educational level found among aphasic patients.

CONSIDERATIONS FOR SPEECH AND LANGUAGE ASSESSMENT OF MULTICULTURAL POPULATIONS FOLLOWING STROKE

Kay T. Payne, Ph.D.

Assessment of speech and language disorders is conducted to quantify and qualify patient behaviors. The clinician's philosophical basis for testing will flavor test selection, administration and interpretation. In addition, a culturally and politically perceived definition of "normal" permeates, and indeed dictates, what is assessed, how behaviors are examined, as well as interpretation of observations.

Clinical assessment of aphasia is directed toward the following determinations: differential diagnosis, syndrome or type of disorder, severity, suitability for treatment and avenues for treatment (Golper, 1996). While a complete description of the disorder is necessary, the ultimate value of assessment lies with its relevance for treatment. Efficacy of treatment is directly related to the quality of assessment.

Numerous epidemiological studies establish the disproportionately higher incidence of stroke and concomitant communication disorders among multicultural populations (American Heart Association, 1994; American Medical Association, 1991; DHHS, Public Health Service, 1994; National Center for Health Statistics, 1993; Saunders, 1991; Wallace, 1993; Yatsu, 1993). Thus, it is imperative that assessment methods and instruments reflect multicultural aspects of communication differences so that treatment outcomes may more adequately address this urgent health situation.

This paper examines cultural biases in existing assessment instruments widely used with African Americans and other multicultural groups. It advocates for consideration of cultural differences in attitudes toward causes of disabilities, as well as outlooks for recovery. It further examines specific test items in relation to various cultural beliefs. Intermediate alternative remedies are provided, yet the need for long-term solutions is defended.

Nature of Cultural Bias

To understand the notion of cultural bias in assessment, several definitions are necessary. First a definition of culture. It is perhaps more efficient to elucidate what culture is not rather than to attempt an all encompassing definition of what culture is. Culture is not race, religion, nationality, ethnicity, linguistic group or social class. Moreover, culture is not merely practices such as holiday celebrations, clothing, artistry, food, etc. Culture is a dynamic abstraction which may entail the above elements, but also incorporates a homogeneity of beliefs, political views, values, cognitive styles and communication systems. As an acute example of culture vs. race, Africans, African Americans and West Indians are racially the same, but distinct on many of the above cultural elements. Culture represents the organization or framework of a singular group's reality. It is the knowledge and cognitive processes which define and dictate a group's behavior.

A definition of bias is also relevant. Bias exists when there is an unintended discrepancy in performance which is observed consistently in a group due to artifacts of the measurement instrument. A cultural bias exists when artifacts of the instrument can be related specifically to elements of culture. Taylor and Payne (1983) list types of bias in standardized speech and language assessments including situational bias, bias in directions or format of the instrument, value bias, stimulus bias, linguistic bias and examiner observation bias. A less obtrusive bias may result from the standardization process, that is, in selection of the norming population.

It is also of importance to examine the distinction between diagnosis and assessment. Diagnosis involves a subjective classification process of placing behavior characteristics into a context in order to determine if a disorder exists and its level of severity, and differentiating its qualities from other conditions with similar characteristics. To a skillful clinician, a diagnosis can be made from observation based upon a definition of aphasia and a general perception of normal communication. Aphasia can be recognizable as a disorder when it is present without regard to culture or language group.

Assessment, or appraisal, is the process of calibrated measurement. Implicit in this definition is the need for a yardstick or standard against which a quantity is held for comparison. Of course, in speech and language assessment, this standard is never based on the linguistic behaviors of multicultural groups. Yet it is firmly established that language is an integral aspect of any culture. In addition, for assessment instruments the concept of normalcy is defined statistically, typically as two standard deviations below the mean performance of the standardization group. However, standardization groups typically do not contain an adequate representation of multicultural groups. Other aspects of a test including its administration procedures and stimulus items may render the instrument culturally biased.

The issues of cultural bias are clear when the instruments are given to children. Biased assessment instruments have resulted in misdiagnosis of communication disorders, misplacement of children in special education and alienation of children due to dialect differences. For adults, however, the issue of cultural bias is not misdiagnosis. The cultural bias in aphasia instruments is related directly to assessment. Since assessment is crucial to the outcome of treatment, culturally biased instruments can lead to inappropriate or improper treatment procedures and unsuccessful outcomes.

At this juncture, it is logical to explore the genesis of cultural bias. Unintended mismatches in the instrument expectations for responses and those expressed by the patient are most often the result of differences in cultural perceptions and beliefs. Figure 1 presents some beliefs and practices of various cultural groups relative to health care and disability.

Figure 1 lists some of the prominent cultural beliefs of five major cultural groups in the U.S. according to health care, causation of illness and attitudes toward disability. It should be noted that, as extracted from Lynch and Hanson, (1992), the beliefs represent traditional cultural tendencies rather than absolutes. This means that within each cultural group, exceptions to these beliefs will be found.

The evidence of Figure 1 is striking in that it reveals that American Indian, African American, Hispanic and Asian beliefs are more similar to each other than beliefs of Anglo-Europeans. Core values of significant difference between Anglo-Europeans and other groups are individual locus of control, or the belief that each person determine his/ her own destiny, and emphasis on science and technology. It is noteworthy that other cultural beliefs based on external (supernatural) locus of control are steadfast and pervasive. Indeed among the more traditional members of other cultural groups, western medical practice is ancillary and secondary to traditional practice.

Cultural biases emerge when western beliefs and practices are held as the standard for assessment instruments and treatment practices. In assessment, western approaches are premised on the basis that test instruments are standardized and that limited observation under strict test administration procedures will yield reliable, valid and predictable results. It is expected that individuals being tested hold this belief and perform according to the test expectations. However, when the beliefs of multicultural groups are considered, it may be observed that scientific explanations are of little value and individuals are not motivated to perform the required tasks of the test.

In treatment, western beliefs hold that disabilities are explainable by science and that they can be prevented and overcome. Yet, members of other cultural groups may believe that disabilities are the result of evil, punishment, misfortune or other sociocultural explanations. Missed appointments, lack of motivation and failure to follow through on assignments may be reflective of these cultural beliefs.

Examination of Test Items

This section presents an examination of four test instruments used to assess patients with syndromes resulting from stroke and other acquired neurological impairment. Several types of bias are noted involving the norming population, as well as the stimulus items. The most prominent bias is that none of the norming populations uses an adequate number of individuals from multicultural groups. In addition, there are no stimulus items in any of the tests which are reflective of the environment of other multicultural groups. Figure 2 gives specific examples of stimulus item bias for the Ross Information Processing Assessment [RIPA] (Ross, 1986); the Boston Assessment of Severe Aphasia [BASA] (Helm-Estabrooks, et al, 1989); the Western Aphasia Battery [WAB] (Kertesz, 1982) and the Boston Naming Test (Goodglass and Kaplan, 1983).

Considering the potentially biased items in Figure 2, the effects can be severely penalizing to multicultural groups. In the RIPA, 24 items are potentially biased. Scores may be depressed for multicultural groups in five of the 10 subtests. Moreover, the RIPA allows the clinician to determine, in addition to raw scores, diacritical scores as follows:

c - **confabulation**: The subject responds with fictitious events or information to fill in memory loss of information gaps.

d - **denial or refusal**: A denial of “ I don’t know”, “No, I can’t”.

dl - **delay**: A delayed or hesitated response.

e - **frank error**: An entirely wrong answer as opposed to a partially correct or incomplete answer.

i - irrelevant: The subject provides an initial correct response and adds further information which is not relevant to the stimulus.

r - repetition: A repeat of task instructions or a stimulus item requested by the subject.

sc - **self-correction:** The subject responds with an error and self-corrects to a correct response without clinician cue or assistance.

t - **tangential:** A correct response is elicited from the subject and is followed by excessive extraneous information not related to the response or the stimulus.

It is obvious that the diacritical scores are extremely subjective and easily subject to misinterpretation of a cultural responses.

The BASA contains seven (11 percent) potentially biased items within a total of 61 items. The WAB contains 28 potentially biased items. Scores would be affected on five subtests including Information Content, Yes/No Questions, Word Fluency, Responsive Speech and Reading.

The Boston Naming Test contains seven potentially biased items of 60 stimulus pictures. Moreover, none of the stimulus items reflect objects in the environment of other multicultural groups.

Intermediate Alternative Solutions

There are no alternative solutions which are easily achieved and currently accessible to the working clinician. Vaughn-Cooke (1983) provides alternatives to the use of assessment instruments with children. Her suggestions range from modifying testing techniques, items and scoring to not using tests which cannot be modified. Also included among her suggestions are using language samples of spontaneous speech and re-norming tests for specific cultural groups.

For the adult aphasic patients, additional alternatives are necessary. There is no dispute that clinicians must learn about the patient's premorbid sociocultural history and linguistic system. Coleman and Wallace (1996) and Holland (1975) discuss the value of ethnography or naturalistic field observations in aphasia assessment. Most scholars would agree, however, that there needs to be some systematic process of analysis of field data and naturalistic speech samples. Thus, there is a need for a uniform procedure of field observation, analysis and triangulation for assessment of language and communication function in aphasic patients.

The use of ethnography in aphasia assessment will require a paradigm shift for clinicians away from what Cooper and Cooper (1994) describe as the "frequency fallacy" that is, a dependence on test scores and rapid administration of test instruments. However, the results of ethnographic assessment will be unquestionably more beneficial to multicultural populations.

Long Term Solutions

The U.S. Census (1990) reports that multicultural groups will comprise almost one-third of the nation in the coming 21st century. As a result, what is currently accepted as the "standard" for assessment, that is, beliefs, values, and language behaviors of Anglo-Europeans, will not be relevant for a sizeable number of individuals with whom tests will be used. Thus, new tests and new assessment foundations which reflect the future demographic makeup of the nation will be imperative.

In order to eliminate cultural bias, stimulus items for future tests must not only be reflective of other cultural groups, but perhaps more importantly, consideration must be given to the very nature of the tasks. Normative samples for new tests must be based not upon population demographics but rather on epidemiological demographics of stroke. In this way, adequate numbers of multicultural groups will be included when the standard is determined statistically.

In order to develop new tests that eliminate cultural bias, much information will be needed about existing tests. Modern technology can be of great assistance. Clinician experiences in using current tests with multicultural populations can be gathered in a national project using the Internet to identify biased items and pitfalls of current instruments to be avoided in creating new tests.

Finally, ethnographic assessment must be understood, accepted, and embraced and taught in training programs. In addition, new research using qualitative methods must be accepted for its scientific value and the in-depth contributions it can make to understanding multicultural groups.

With the changing demographics, it will be necessary for scholars to reassess what is considered as current knowledge with direct reference to relevance to multicultural groups. While new qualitative studies will reveal specific information about cultural groups, foundational studies from which assessment principles are drawn must then be replicated to affirm their applicability to other cultural groups. With these and other creative solutions, the field of aphasiology will take a new turn in the direction of the 21st century and beyond.

FIGURE 1

Cultural Values and Beliefs Toward Health Care and Disability

	Anglo-Europeans	American Indians	African Americans	Hispanics	Asians
Health Care	value on technology emphasize prevention desire to prolong life pharmaceutical treatment	tribal healers ceremonial rituals	lack of access home remedies technology for trauma situations	natural healers spiritualists symbolic rituals use of amulets	spiritual ceremonies herbal medications accupuncture
Causation	individual locus of control non-fatalistic	external locus of control fatalistic multiple causality supernatural events disturbance of balance	punishment from deity work of the devil fatalistic	works of evil fatalistic folk beliefs	supernatural focus on symptoms rather than cause folk beliefs punishment
Disability	scientific causes preventable self-help use of compensatory devices	sociocultural explanation of cause	due to misfortune acceptance	"act of God" acceptance related to socio-economic status	viewed with considerable stigma

Source: Lynch, E. and Hanson M. (1992)

FIGURE 2

POTENTIAL ITEM BIAS IN TESTS OF APHASIA AND COGNITIVE PROCESSING

TEST: ROSS INFORMATION PROCESSING ASSESSMENT (RIPA)

SUBTEST	ITEM#	
II	1-4	How long have you been in this hospital?
Recent Memory		What month is it?
		What day of the week is it?
		What building are you in?
III	1-10	
Temporal Orientation		What year is it?
		What season are we in?
		What month is it?
		What was last month?
		What date is it?
		What day of the week is it?
		About what time is it?
		What was our last holiday?
		How long have you been in the hospital?
		BIAS: Certain individuals of American Indian decent may respond with silence to obvious questions.
VII		
Recall of General Information		
	6	What war involved the North and South?
		BIAS: Different answers may be given for Koreans, Vietnamese, and other immigrants.
	7	Who was the first president?
		BIAS: Not common knowledge for many immigrants.
	8	Who discovered America?
		BIAS: African Americans and American Indians may not acknowledge Christopher Columbus.
	10	Who was Helen Keller?
		BIAS: While commonly known to most Anglo-Europeans, this may not be known by other cultural groups.
VIII		
Problem Solving and Abstract Reasoning	7	What does "Don't cry over spilled milk" mean?
	8	What does "Waste not, want not" mean?
		BIAS: Idioms of English are not familiar to speakers of other languages.
IX		
Organization	1	Name as many animals as you can in one minute.
	2	Name as many fruits as you can in one minute.
	3	Name as many states as you can in one minute.
	4	Name as many foods as you can in one minute
		BIAS: Some cultures such as American Indians display contemplation before answering question. Other cultures such as African Americans and Hispanics do not perceive time as monochronic.

FIGURE 2 (CONTINUED)

TEST: BOSTON ASSESSMENT OF SEVERE APHASIA (BASA)

ITEM #	
4	What happened to you? BIAS: Beliefs about causation may differ for African Americans, Hispanics, Asians and other cultures. Accordingly patients may be reluctant to answer or give nontraditional explanations.
17	Could you sing "Row, Row, Row Your Boat"? BIAS: May be unfamiliar to immigrants and speakers of other languages.
24	Show me how you salute (or pledge allegiance to the flag).
25	Show me how you shake your finger at a naughty child. BIAS: Both gestures may be unfamiliar to many cultures.
47	Who is this: Adolf Hitler, WC. Fields, Marilyn Monroe. Alternates:The Honeymooners, John Wayne, Clark Gable BIAS: Adolf Hitler may be offensive to Jews and WWII veterans. Personalities may be unfamiliar to many cultures.
54	Tell me what this is: Swastika BIAS: May be unfamiliar to many, offensive to Jews and African Americans, embarrassing to German immigrants.
55	Match swastika and Hitler BIAS: May be unfamiliar to many, offensive to Jews and African Americans, embarrassing to German immigrants.

FIGURE 2 (CONTINUED)

TEST: WESTERN APHASIA BATTERY (WAB)

SUBTEST	ITEM #	
I Information Content	2-4	Have you been here before? What is your name? What is your address?
	6	Tell me a little about why you are here or what seems to be the trouble.
		BIAS. Certain individuals of American Indian descent may respond with silence to obvious questions.
II Yes/No Questions	1-20	Is your name Smith? Is your name Brown? Do you live in Toronto? Are you a man or a woman? Are you a doctor? Am I a man or a woman? Are the lights on in this room? Are you wearing red pajamas? Is this a hotel?
		BIAS: Certain individuals of American Indian descent may respond with silence to obvious questions.
IV. B Word Fluency		Ask the patient to name as many animals as he or she can in 1 minute. The patient may be helped if hesitant: "Think of a domestic animal, like the horse, or a wild animal, like the tiger." The patient may be prompted at 30 seconds
		BIAS: Some cultures such as American Indians display contemplation before answering question. Other cultures such as African Americans and Hispanics do not perceive time as monochronic.
IV. D Responsive	1	What do you write with? (pen, pencil) Speech
	2	What color is snow? (white)
	3	How many days are in a week? (seven)
	4	Where do nurses work? (hospital)
	5	Where can you get stamps? (post office, variety store)
		BIAS: Certain individuals of American Indian descent may respond with silence to obvious questions.
V. A Reading	7	Energy used to be relatively plentiful. Due to oil shortage, many nations are turning to alternate sources such as...boiling water, the banks, the sun, economy BIAS: "Nations" may be ambiguous to American Indians, e.g., Indian nations, thus banks may be an obvious choice.
	8	The Titanic was an oceanliner which was thought to be unsinkable but it hit an iceberg and sank in 1912, killing over a thousand people. It would not have sunk if it had not...lost power been badly damaged carried passengers been going west
		BIAS:To individuals unfamiliar with the Titanic, any or all of the answers might be selected.

FIGURE 2 (CONTINUED)

TEST: BOSTON NAMING TEST

ITEM #	
14	Mushroom
30	Harmonica
40	Knocker
41	Pelican
49	Asparagus
57	Trellis
60	Abacus

BIAS: The expected response may be different for African American patients e.g.,

Mushroom -Toodstool

Harmonica -Mouth organ

Abacus - Counter

Proper names of other items may be unfamiliar such as pelican, asparagus, trellis, and abacus.

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TREATMENT OF APHASIA: ADDRESSING CULTURAL DIFFERENCES AMONG PATIENTS

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The fastest growing cultural groups in the United States are Hispanic and Asian. In 1950, 75 percent of the minorities in this country were African-American. It is predicted that by the year 2010 the number of Hispanic-Americans will surpass all other groups and Anglo Americans will become a minority (1). Despite the realities and forecasts, in our clinical training programs we provide students with little or no cultural-specific information for working with aphasic individuals. Furthermore, it would appear that aphasia treatment methods have been developed and applied almost exclusively to Anglo-American patients. We appear not to have recognized the need for a framework for addressing culture-specific concerns in aphasia treatment even though "culture" plays prominently in the World Health Organization definition of quality of life: "An individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns" (2).

In seeking a framework useful for working with individuals from any cultural group we can turn to the field of cross-cultural psychology where Breslin and Yoshida (3) provided a model incorporating eight basic concepts or cultural-specific knowledge themes. In this paper, I review the Breslin and Yoshida model and present some implications of their eight cultural-specific concepts for treatment of aphasic persons.

1. Individualism vs Collectivism. In considering any culture we can determine whether it is individualistic or collective by asking how the culture is set up; where the ultimate value is placed; who sets the goals. In individualistic cultures (primarily North American and European) persons set their own goals; they speak for themselves. In collectivism (primarily American Indian, Latin American and Asian), it is the group who speaks for the individual; sets the goals.

One implication of this concept for aphasia treatment is in setting functional goals which is of foremost importance in today's health care environment. In establishing functional goals for patients from individualistic cultures it is important to determine the desires of the persons themselves; we must always seek direct input from these patients. In establishing functional goals for patients from collective cultures, we must seek information from the members of the greater family (which may include second and third degree relatives) as well as from the patients themselves.

2. ***Work.*** In individualistic cultures, persons are defined by their jobs; the kind of work they do. In collectivism, it is the person's social obligations and deeds that are important. Within a individualistic workplace, about 80 percent of the time will be task directed and 20 percent will be social. These allotments are quite different in collectivism where strong social networks must be maintained in order to accomplish deeds.

One implication of the concept of work for aphasia treatment is that in individualistic societies the rehabilitation goals for non-retired patients are likely to be vocational; to return the patient to work. Inability to work typically has great financial and psychological consequences requiring assistance from counsellors and social workers. The inability to return to work may not have the same financial and psychological implications for aphasic patients from collective societies where the group provides support. The goal of therapy may focus instead on preparing patients to successfully reenter their social networks.

3. ***Time & Space.*** In terms of time, cultural differences are viewed as "clock time" versus "event time." Individualism stresses clock time; people carry date books, make appointments, keep appointments. Punctuality is a virtue and tardiness is a vice. In collectivism it is events that are paramount with no setting of, or adherence to, strict time-frames.

Our clinics are very clock-time specific. The starting and ending times of treatment sessions are predetermined and adhered to even though a patient may be showing excellent response and would benefit from an extended session, or poor response and should be allowed to discontinue. Although we may not be in the position to change this approach, it is important to acknowledge the rights of the patient from a collective society to assign greater importance to events other than the rigidly timed therapy session within earning labels such as "unmotivated," "uncooperative" or "disorganized."

In cultural terms, the concept of space refers to the distance persons stand from one another during a conversation. In Latin America, for example, the typical interpersonal space is 18" versus 36" in American and Japanese societies.

The implication of "space" for aphasia treatment are highly pragmatic. Appropriate positioning of clinicians and patients according to their cultural norms will enhance the comfort level of treatment sessions.

4. ***Language.*** The issue of language, of course, is of critical importance to treatment of aphasia, a language disorder. Some of the sub-issues of cultural differences in language use include that of formal versus informal language, pragmatics, and nonverbal behaviors.

For dedicated clinicians who attempt to learn a new language to work with their patients, it is important to note that language as it is learned in courses, books, and tapes may not teach important informal modes of communication including gestures. This point also applies to the vocabulary used in English-speaking sessions where we might spend time training phrases such as "good afternoon" even though this greeting may rarely be used in this society where "hi" prevails.

5. ***Roles.*** The concept of roles refers to the behaviors that are expected from people having a certain title in a particular society. In some societies, healers have spiritual qualities, bond closely with those they are trying to heal, and may stay physically close to their "patients" until recovery is achieved. This differs dramatically with practitioners of Western medicine for whom scientific, not spiritual, attributes are valued and who have no personal relationship with their patients.

Roles are highly important to aphasia rehabilitation in terms of goal-setting for patients vis a vis the behaviors that are expected from them according to the roles they play. For example, in some cultures the role of grandparent has high expectations of wisdom, child caring and other highly prized contributions to the family. In other cultures, grandparents are relegated to an armchair in the corner of the room where they are rarely spoken to. Our own roles as clinicians may change according from patient to patient in view of their cultural membership. For example, patients from individualistic societies may need us to be advocate, social worker, vocational counsellor and friend because they have little or no support from their society.

*6. **Rituals and Superstitions.*** Rituals are familiar ways of achieving goals and may be used to help people get through the day successfully. Superstition is a pejorative term that is applied to the rituals of persons from different cultures.

Knowledge of our patients' rituals is of great functional importance. This may be especially true in preparing patients to live within an extended care facility where successful transition may depend on how well familiar routines are established.

*7. **Social Class.*** Social class refers to one's status within a culture; the place of respect in that society. Individualistic cultures determine status according to one's income, job prestige, neighborhood, and level of education. In collectivism, one's family and family name are important and status may be elevated according to the number of rituals learned. Aphasia may greatly jeopardize the social status of patients from individualistic cultures.

Aphasia rehabilitation specialists must be aware of any such consequences and be prepared to help these patients cope with changes in their social status. In contrast, persons from collective cultures may experience little or no change in social class as a result of aphasia.

*8. **Values.*** Values refer to a society's desirable end states; what is important in terms of achievement, e.g. money, friends, wisdom, power.

An implication of the concept of values for aphasia treatment is that we have an obligation to determine what is important to our patients. The use of pictures, job-related information, printed materials from their places of worship or clubs may be gathered into scrap books that allow patients to identify and express their values without requiring them to talk about them.

In using Breslin and Yoshida's model as a framework for treating aphasic patients from various cultural background, the concepts of individualism versus collectivism have played prominent roles. It is important to note, however, that we cannot assume that a patient from an individualistic culture will not live according to many of the principles of a collective society and vice versa. Rather, we can use Breslin and Yoshida's eight cultural-specific knowledge themes to guide our work with any aphasic patient without preconceived notions of what she or he considers important and what the goals of therapy should be.

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USAGE AND ACCESS TO REHABILITATIVE SERVICES BY MINORITY POPULATIONS

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Twelve percent of the U.S. population is currently considered "elderly" and therefore prone to the types of communication disorders that serve as the focus of this conference. Within the near future, this is projected to increase to 20 percent. By the year 2000, 25 percent of the elderly in the U.S. are projected to be members of minority groupings. These "minority elders" are considered by some to be portions of the U.S. population that are "a minority within a minority" implying that later in life, the effects of racial discrimination are combined with ageism so as to have a cumulative negative effect on the availability of health resources (Dowd and Bentson, 1978; Williams, 1980). What might be barriers that currently inhibit access and utilization of rehabilitative services by patients who have suffered neurologic events, and specifically those that result in communicative disorders? While minority populations equaled approximately 19 percent of the U.S. population in 1991, only 3.7 percent of ASHA members who are clinicians are Black, Hispanic, Asian or Native American (ASHA, 1992). Clearly this means that individuals suffering from communication disorders such as those resulting from neurologic events are likely to see speech/language pathologists who do not share their ethnic background. Can we assume that speech/language pathologists who are not Black, Hispanic, Asian or Native American have taken the opportunity to prepare for the unique attributes of these minority, clinical populations? Campbell and colleagues (1989) report that 66 percent of the 713 speech/language pathologists they polled stated they were not trained in multicultural issues.

And what is known about the characteristics of these minority populations that might impact the effectiveness and outcome of treatment attempts? The U.S. House of Representatives Select Committee on Aging noted that approximately 80 percent of the frail elderly are cared for by family lay caregivers. What is known about the Black, Hispanic, Asian or Native American therapeutic process? For example, Hispanic culture holds the family unit as the primary focus of daily life. Extended families often live in a single home, and most of life's circumstances embrace group involvement with group decision making occurring including health care decision making. Clearly, this family involvement should be one that is recruited and very intimately utilized in the therapeutic process. In contrast, those of an Asian culture may view instances of failure (especially in a mental capacity) as something shame provoking and not easily exposed, especially to family members. And the ability to inform the therapeutic process by research on minority populations is not simply unidirectional in that it may not only inform us about how to maximize the functioning of minority patients but nonminority as well. For example, Morucz and colleagues (1987) looked at caregivers of patients with Alzheimer's disease and reported less strain when caring for elders with dementia than White caregivers. What might be the basis for this difference and how can the principles learned be applied to all populations? These issues will serve as the basis for advocating for a research initiative that focuses on those factors that are culturally based that may encourage or inhibit the therapeutic process in patients with communicative disorders resulting from neurologic impairments.

COMPARISONS OF APHASIA IN AFRICAN-AMERICANS AND CAUCASIANS

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There is considerable literature that indicates the incidence of stroke is higher in African-Americans than in Caucasians even after adjusting for age, hypertension, and diabetes mellitus (Kittner, McCarter, Sherwin, et al., 1993). Physical and functional impairment subsequent to stroke is significantly more severe in African-Americans than in Caucasians (Horner, Matchar, Divine, and Feussner, 1991); improvement in physical impairment is less; and improvement in functional impairment is slower. However, observation of functional deficits in African-American stroke patients and comparison with Caucasian stroke patients has focused on activities of daily living. Only one report (Wertz, Auther, and Ross, 1997) has compared aphasia in African-American and Caucasian stroke patients.

Several problems complicate comparison of severity and prognosis for improvement in aphasia between African-American and Caucasian stroke patients. First, even though a higher risk and incidence of stroke in African-Americans than in Caucasians does not dictate more severe aphasia or a poorer prognosis for improvement, increased general morbidity subsequent to stroke in African-Americans may result in more severe aphasia and less improvement.

Second, possible premorbid racial differences may influence the severity of and improvement in aphasia subsequent to stroke. For example, Jackson (1985) suggests development and aging differ between African-Americans and Caucasians, and the results of Wallace's (1993) survey of neurological impairment among elderly African-American and Caucasian nursing home residents may demonstrate the influence of these variables on the type of neurological impairment that occurs.

Third, the measures used to assess severity and improvement in aphasia may be culturally biased (Anderson and Ulatowska, 1978; Taylor, 1992; Wallace, 1996). Aphasia tests, for the most part, were standardized on educated, middle class Caucasians. Thus, linguistic diversity in African-Americans may be ignored or penalized by these measures.

And, fourth, if treatment for aphasia influences improvement, availability and utilization of treatment, as well as, the nature and content of the treatment provided may result in differences in improvement between African-Americans and Caucasians. Kenton (1991) implies access to neurological care differs among races, and Harris (1992) speculates African-Americans, especially older African-Americans, may be less likely to utilize treatment resources that are available. Moreover, Wallace (1996) observes that clinicians who treat aphasia may not be knowledgeable about multicultural issues and, therefore, employ only their own cultural experience in the treatment they administer.

The purpose of this presentation is to summarize our previous report (Wertz, Auther, and Ross, 1997) that compared severity of and improvement in aphasia between African-Americans and Caucasians and to present an additional comparison of aphasia between African-Americans and Caucasians.

Previous Report

We (Wertz, Auther, Ross, 1996), reviewed performance by patients who participated in the first, Veterans Administration (VA) cooperative study on aphasia (Wertz, Collins, Weiss, et al., 1981) and compared severity of aphasia at one month postonset, improvement in aphasia during the first year postonset, and rate of improvement between African-Americans and Caucasians. Patients in that study met the following selection criteria: 40-80 years of age; premorbidly able to read and write English; aphasic subsequent to a first, thromboembolic CVA; damage confined to the left hemisphere; no coexisting major medical complications; hearing no worse than a 40db SRT in the poorer ear; vision no worse than 20/100 in the better eye, corrected; able to gesture and write with at least one hand; four weeks postonset at entry in the study; and language severity from the 15th to the 75th Overall percentile on the Porch Index of Communicative Ability (PICA) (Porch, 1967) at entry.

All African-American and Caucasian patients entered in the VA Cooperative Study who had received at least 11 weeks of treatment, from entry at four weeks postonset to 15 weeks postonset, during the 44-week treatment trial were selected. Samples of 35 Caucasians and 15 African-Americans were obtained using this criterion.

Mean age at entry in the VA cooperative study (four weeks postonset) was 59.1 years for African-Americans and 58.8 years for Caucasians. Mean years of education was 9.3 years for African-Americans and 11.4 years for Caucasians. Mean PICA Overall performance was at the 35th percentile in African-American patients and at the 39th percentile in Caucasian patients. There were no significant differences ($p < .05$) in age, education, or severity of aphasia on the PICA between groups.

Three language measures—the PICA; a word fluency measure (Borkowski, Benton, and Spreen, 1967) that required the patient to say all of the words he or she could think of, in one minute, that begin with a specified letter ("s," "t," "p," "c"); and the Token Test (DeRenzi and Vignolo, 1962) were administered at entry (four weeks postonset) and after every 11 weeks of treatment (15, 26, 37, 48 weeks postonset) during the 44-week treatment trial.

Study patients were assigned randomly to either individual or group treatment for six to eight hours each week for 44 weeks. Individual treatment included traditional, stimulus-response manipulation of language deficits in all modalities. Group treatment involved conversation and discussion in groups of four to seven patients with no direct manipulation of speech and language deficits.

Four of the 15 African-American patients received individual treatment, and 11 received group treatment. Nineteen of the 35 Caucasian patients received individual treatment, and 16 received group treatment. Attrition during the

44-week treatment trial was 47 percent for African-American patients and 37 percent for Caucasian patients. The most common reasons for dropping out were having to remain hospitalized or having to drive long distances to receive treatment. Reasons for dropping out did not differ between African-American and Caucasian subjects.

Significant differences in improvement in the VA cooperative study between individual and group treatment were few. Those that occurred were confined to the PICA, where individually treated patients made significantly more ($p < .05$) improvement than group treated patients at specific points during the 44-week treatment trial (Wertz et al., 1981). We combined individual and group treated patients in our analyses that compared aphasia in African-Americans and Caucasians.

Our first purpose was to compare initial severity of aphasia at four weeks postonset, prior to the initiation of treatment, between African-Americans and Caucasians. **These data are shown in Table 1.** No significant differences ($p < .05$) on the PICA Overall, Gestural, Verbal, or Graphic modality percentiles were observed between groups. Similarly, no significant differences ($p < .05$) were observed for word fluency and Token Test total scores between groups.

We employed intent to treat analyses to compare severity between groups at the end of the 44-week treatment trial, 48 weeks postonset. **As shown in Table 2**, there was no significant difference between groups on the PICA Overall score or Verbal modality score, Word Fluency Measure, or Token Test. However, African-American subjects performed significantly lower than Caucasian subjects on the PICA Gestural modality score ($p < .05$)and the PICA Graphic modality score ($p < .05$).

Our second purpose was to compare the amount of improvement in aphasia obtained by African-American and Caucasian patients during the 44-week treatment trial. **These data are shown**

TABLE 1. **Mean severity on the outcome measures at four weeks postonset for African-American (AA) and Caucasian (C) aphasic patients.**

MEASURE	GROUP MEAN		MEAN DIFFERENCE
	AA	C	
PICA Overall	9.48	9.89	- .41
Gestural	11.51	12.07	- .56
Verbal	9.57	8.55	+ 1.02
Graphic	6.71	7.68	- .97
Word Fluency	6.80	6.97	- .17
Token Test	16.87	24.77	- 7.90

TABLE 2. Mean severity on the outcome measures at 48 weeks postonset for African-American (AA) and Caucasian (C) aphasic patients.

MEASURE	GROUP MEAN		MEAN DIFFERENCE
	AA	C	
PICA Overall	11.24	11.98	- .74
Gestural	12.81	13.44	- .63*
Verbal	11.75	11.74	+ .01
Graphic	8.82	10.30	- 1.48*
Word Fluency	12.07	15.31	- 3.24
Token Test	25.60	36.11	- 10.51

*Significant at p < .05

in Table 3. Intent to treat analyses, using a separate analysis of variance for each measure, indicated both groups improved significantly (p<.001) between four and 48 weeks postonset on all PICA percentiles, and there were no significant differences (p<.05) between groups in the amount of improvement made on any PICA measure. Similarly, both groups improved significantly (p < .001) in word fluency and Token Test performance, and there was no significant difference (p<.05) between groups in the amount of improvement on either measure.

Our third purpose was to compare the rate of improvement in aphasia between African-American and Caucasian patients. **Table 4 shows the percent of total,** mean improvement in the PICA Overall and Modality scores at each evaluation date. Both groups improved over time, and there was no significant (p<.05) time by group interaction. Similar results (Table 4) were observed for change in word fluency total scores—significant improvement over time in both groups and no significant (p<.05) time by group interaction—

TABLE 3. Mean improvement on the outcome measures between four and 48 weeks postonset for African-American (AA) and Caucasian (C) aphasic patients.

MEASURE	GROUP MEAN		MEAN DIFFERENCE
	AA	C	
PICA Overall	1.76	2.09	-.23
Gestural	1.30	1.37	- .07
Verbal	2.18	3.19	-1.01
Graphic	2.11	2.62	- .51
Word Fluency	5.27	8.34	- 3.07
Token Test	8.73	11.34	- 2.61

TABLE 4. Percent of total, mean improvement on the outcome measures for African-American (AA) and Caucasian (C) aphasic patients at each evaluation date between four and 48 weeks postonset.

MEASURE	GROUPS BY TIME							
	15 Weeks		26 Weeks		37 Weeks		48 Weeks	
	AA	C	AA	C	AA	C	AA	C
PICA Overall	58	65	66	86	83	94	100	100
Gestural	67	63	77	79	91	98	100	100
Verbal	71	68	77	97	86	97	100	100
Graphic	42	68	50	89	77	89	100	100
Word Fluency	76	66	100	85	100	100	100	100
Token Test	83	86	83	86	96	100	100	100

and for Token Test total scores—significant improvement over time in both groups and no significant ($p < .05$) time by group interaction.

A summary of the results indicates there was no significant difference in initial, four weeks postonset, severity of aphasia between African-American and Caucasian aphasic patients. However, at 48 weeks postonset, African-American aphasic patients performed significantly lower than Caucasian aphasic patients on the PICA Gestural and Graphic modality scores. Both groups made significant improvement during a 44-week treatment trial, and there was no significant difference between groups in the amount of improvement attained. And, there were no significant differences between groups in the rate of improvement.

Present Report

Subsequently, we reviewed study patients from the second Veterans Administration cooperative study on aphasia (Wertz, Weiss, Aten, et al., 1986) and asked questions about differences in aphasia between African-Americans and Caucasians. Our purposes were: to compare initial severity of aphasia, improvement in aphasia after receiving 12 weeks of treatment during a 24-week treatment trial, and severity at the end of the treatment trial between samples of African-American and Caucasian aphasic patients.

Study patients met the following selection criteria: age, 75 years or younger; literacy, premorbidly able to read and write English; etiology, first thromboembolic CVA; localization, damage confined to the left hemisphere; medical status, no coexisting major medical complications; weeks postonset, between two and 24 weeks at entry; sensory status, hearing no worse than a 40db speech reception threshold in the poorer ear, vision no worse than 20/100 corrected in the poorer eye, and sensory and motor ability sufficient in one upper extremity to write and gesture; language severity, from the tenth through 80th overall percentile on the PICA at entry; and living in a noninstitutionalized environment.

The 26 African-American aphasic patients who participated in the second, VA cooperative study were selected, and a sample of 35 Caucasian aphasic patients, matched for age, education, and weeks postonset of aphasia with the African-American sample, was selected for comparison from the 95 Caucasian patients entered in the VA cooperative study.

Mean age at entry was 55.08 years for African-Americans and 57.94 years for Caucasians. Mean years of education was 10.23 years for African-Americans and 11.6 years for Caucasians. Mean weeks postonset was 7.46 weeks for African-Americans and 7.26 weeks for Caucasians. The groups did not differ significantly ($p<.05$) in age, education, or weeks postonset.

All patients had been entered in a 24-week treatment trial designed to administer 12 weeks of treatment, eight to ten hours each week between entry and 12 weeks or 12 weeks and 24 weeks. Some of the patients were treated by speech-language pathologists, and some were treated by trained volunteers. Because the results of the VA cooperative study indicated no significant differences in improvement between patients treated by speech-language pathologists and trained volunteers or in ultimate improvement obtained at 24 weeks between patients treated early, first 12 weeks, or late, second 12 weeks, patients in all treatment groups were combined for the present comparisons.

A battery of outcome measures—PICA; Communicative Abilities in Daily Living (CADL) (Holland, 1980); Functional Communication Profile (FCP) (Sarno, 1969); Reading Comprehension Battery for Aphasia (RCBA) (LaPointe and Horner, 1979); and the Token Test (Spreen and Benton, 1969) was administered at entry and at six, 12, 18, and 24 weeks after entry. Patient performance at entry, pretreatment, and at 24 weeks, post-treatment, was used for comparisons between groups.

Sample size for both groups changed, because of attrition, during the 24-week treatment trial. Total attrition was 21 percent. Six, 23 percent, of the African-American and seven, 20 percent, of the Caucasian aphasic patients dropped out prior to completing the treatment trial.

Our first question was about the initial severity of aphasia for the African-American and Caucasian groups at entry. As shown in Table 5, African-American patients performed significantly lower in the PICA Gestural ($p < .03$) and Graphic ($p < .04$) modalities. There was no significant difference between groups in the PICA Overall score or the Verbal modality score. Initial severity between groups did not differ significantly on the CADL, FCP, or Token Test. However, African-American patients performed significantly lower ($p < .001$) than Caucasian patients on the RCBA.

Our second question, inquired about differences in improvement of aphasia between African-Americans and Caucasians. As shown in Table 6, both groups made significant improvement ($p < .0001$) on all PICA measures between entry and the end of the 24 week treatment trial, and there was no significant difference ($p < .05$) between groups in the amount of improvement obtained on any PICA measure. Similarly, both groups made significant improvement ($p < .0001$) on the CADL, FCP, RCBA, and Token Test between entry and the end of the 24-week treatment trial, and there was no significant difference ($p < .05$) between groups in the amount of improvement obtained on any of these measures.

Our third question, involved severity of aphasia in African-Americans and Caucasians at the end of the 24-week treatment trial. As shown in Table 7, after receiving treatment, African-Americans displayed significantly lower PICA Overall and Gestural modality scores ($p < .05$) than Caucasians. There were no significant differences ($p < .05$) between groups in PICA Verbal and Graphic modality performance. On the other outcome measures, African-Americans displayed significantly lower ($p < .005$) RCBA performance than Caucasians. There were no significant differences ($p < .05$) in severity between groups on the CADL, FCP, or Token Test.

Our results indicate African-American aphasic patients displayed significantly more initial impairment, at approximately eight weeks postonset, in gesture, writing, and reading

TABLE 5. Mean severity on the outcome measures at entry for African-American (AA) and Caucasian (C) aphasic patients.

MEASURE	GROUP MEAN		MEAN DIFFERENCE
	AA	C	
PICA Overall	9.50	10.41	- .91
Gestural	11.42	12.45	-1.03*
Verbal	8.46	8.83	- .37
Graphic	7.70	8.76	-1.06*
CADL	77.62	92.48	-14.86
FCP	49.17	48.71	+.46
RCBA	53.11	69.17	-16.06**
Token Test	93.00	94.20	-1.20

* Significant at $p < .05$
** Significant at $p < .001$

TABLE 6. Mean improvement on the outcome measures during the 24-week treatment trial for African-American (AA) and Caucasian (C) aphasic patients.

MEASURE	GROUPS		MEAN DIFFERENCE
	AA	C	
PICA Overall	1.55	1.70	- .15
Gestural	.99	.85	+ .14
Verbal	2.14	2.45	- .31
Graphic	5.75	2.12	+ 3.63
CADL	17.20	16.64	+ .56
FCP	10.20	13.51	- 3.31
RCBA	14.19	13.46	+ .73
Token Test	16.28	30.44	- 14.16

TABLE 7. Mean severity at the end of the 24-week treatment trial for African-American (AA) and Caucasian (C) aphasic patients.

MEASURE	GROUPS		MEAN DIFFERENCE
	AA	C	
PICA Overall	11.05	12.11	- 1.06*
Gestural	12.41	13.30	- .89*
Verbal	10.60	11.28	- .68
Graphic	13.45	11.07	+ 2.38
CADL	94.82	109.12	- 14.30
FCP	59.37	62.22	- 2.85
RCBA	67.31	82.63	- 15.32**
Token Test	110.52	126.18	- 15.66

* Significant at $p < .05$
** Significant at $p < .005$

than Caucasian aphasic patients. African-American and Caucasian aphasic patients made significant improvement during the treatment trial, and there was no significant difference between groups in the amount of improvement attained. At the end of the treatment trial, after both groups had received 12 weeks of treatment, overall, gestural, and reading abilities were significantly more impaired in African-American aphasic patients than in Caucasian aphasic patients.

Discussion

What may we conclude from the results of these two comparisons of aphasia in African-Americans and Caucasians? They show similarities and differences. In the first study, we found no significant difference in initial severity of aphasia between African-Americans and Caucasians. In the second study, we observed African-Americans displayed significantly more initial severity of aphasia on some measures than Caucasians. In both studies, African-Americans displayed significantly more impairment than Caucasians on some measures at the end of the treatment trials.

A difference between the two investigations was the time when initial severity was measured. In the first study, comparison between groups was made at four weeks postonset. In the second study, comparison was made at approximately eight weeks postonset. Whether this might explain the difference in results, we do not know. Finding out would require monthly evaluations during the first few months postonset.

The presence of more impairment in African-Americans than in Caucasians at the end of treatment in both studies may result from using intent to treat analyses. This analysis employs the principal "once randomized, always analyzed" (Wertz, 1995). Thus, intent to treat analysis requires all subjects be included in endpoint analyses even if they did not receive the amount and duration of treatment prescribed. There was no significant difference in the number of dropouts between groups in either investigation. However, more (47 percent) African-Americans dropped out of the first study than Caucasians (37 percent). Similarly, slightly more African-Americans (23 percent) dropped out of the second study than

Caucasians (20 percent). Early termination may have affected the endpoints severity, 48 weeks and 24 weeks, without influencing the amount of improvement between groups from four to 48 weeks in the first study and approximately eight to 32 weeks in the second study.

A similarity between the two comparisons is that aphasia improves significantly in both African-Americans and Caucasians, and there is no significant difference between groups in the amount of improvement attained. This differs from previous reports (Gillum, 1988; Horner et al., 1991) on improvement in physical and functional impairment, where African American stroke patients displayed slower functional improvement and less physical improvement than Caucasian stroke patients.

Both of our investigations were retrospective. The data come from studies that were not designed specifically to compare aphasia in African-American and Caucasian aphasic people. There is a need for prospective research specifically designed to examine severity and improvement of aphasia in African-Americans and Caucasians. And, these efforts may want to explore the possibility of cultural bias in the outcome measures employed, as well as, the availability and utilization of rehabilitation services by the study patients.

Acknowledgments

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QUALITY OF LIFE ISSUES FOLLOWING STROKE

Martin L. Albert, M.D., Ph.D.

In this final session of the meeting before the summary by Dr. Anderson, Drs. Kazis and Frattali and I will be focusing on Quality of Life issues following stroke, and to the extent possible, on aphasia-producing strokes in African-American and other cultural groups. Quality of Life, of course, is multidimensional; and we shall each address a different aspect. Dr. Kazis will emphasize approaches to assessing Quality of Life. Dr. Frattali will explain ways in which stroke rehabilitation may be extended beyond the traditional borders of the medical model, in an attempt to deal with culturally defined needs, preferences, and support systems. And I will focus on two elements: first, ways in which the brain damage itself influences Quality of Life; second, psychosocial issues.

This conference was organized to evaluate the need for research on communication disorders and stroke in African-American and other cultural groups and to define research directions for the future. In this context, I can give you my conclusion at the beginning. I could find virtually no research on the ways in which brain damage influences Quality of Life specifically focusing on African-American and other cultural groups. None! If you think that this will be an important health related topic for our country in the next century, as I do, then I think we have discovered a remarkable lacune in our knowledge, and an important area for future research.

Let me tell you what I did find. The key points of my talk are as follows:

Type and location of brain damage following stroke always influence patient-caregiver interactions and, ultimately, Quality of Life.

And, psychological maladaptations often occur early after stroke, and if not dealt with effectively, are long-standing.

The most well studied aspect of how brain damage influences Quality of Life following stroke has to do with the hemisphere involved. We all know that left hemisphere lesions cause aphasia in most people, and that right hemisphere lesions do not. Despite the problems with communication following left hemisphere lesions, it is the patients with right hemisphere lesions who have greater deterioration in Quality of Life. This probably arises from the fact that the right hemisphere is dominant for attentional mechanisms which are linked to awareness of deficits. Patients with right hemisphere lesions are less likely to be aware of their deficits (such as left sided hemiplegia) and are, therefore, less likely to work effectively in post-stroke rehabilitation programs.

Right hemisphere lesions also produce a syndrome called "motor impersistence," in which a person will be unable to continue carrying out a motor act to its adequate completion.

These two neurobehavioral phenomena—unawareness of illness and motor impersistence—are beyond the voluntary control of the patient, that is, they are not the patient's fault. However, they are extremely frustrating for the caregiver or therapist, and they are difficult for the caregiver to accept emotionally. I remember the husband of one of my patients with a left hemiplegia due to a right hemisphere stroke. He was a professor of history at a well-known university in Cambridge. As he was about to take his wife home from the hospital, after the daily conversations we had during the acute stage of her illness, we spent about an hour talking about her medical condition. I drew pictures of the brain, and I tried to help him understand her strengths and weaknesses. At the first follow-up visit, he took me aside and said, "Look, Dr. Albert, I have to ask you a question. I understand what you said about neglect and unawareness of illness, and motor impersistence. The problem is, I just can't understand why she doesn't try harder."

A different type of influence on patient-caregiver interaction and Quality of Life results from aphasia-producing strokes in the left hemisphere. Frontal lesions which cause non-fluent aphasias, like Broca's Aphasia, are associated with depression; while lesions in the temporal and temporo-parietal regions, which cause fluent aphasias with comprehension deficits, like Wernicke's Aphasia, cause a different set of psychological reactions. Typically there is a mild euphoria at first, followed by progressive irritability, and, in some cases, ending in paranoia. Here again, we are talking about neurobehavioral phenomena related to lesion location. You can just imagine how a caregiver might feel, with his or her life in turmoil because a loved one has suddenly developed aphasia, now having to deal with the psychiatric complications as well.

A couple of years ago several of us at the Aphasia Research Center decided to look at this problem more closely. We administered the Boston Diagnostic Aphasia Examination to a group of aphasic subjects and three Quality of Life questionnaires to their caregivers. We were rather surprised by the results. We found the aphasia itself, even severe aphasia, was not correlated with caregiver stress. However, caregiver stress was correlated with two other factors: First, the amount of depression that the aphasic patient had, and second, the amount of difficulty in activities of daily living that the aphasic patient had.

So far, I've been talking about the effect of hemispheric side of lesion on patient-caregiver interactions. We also know that lesions in the frontal lobes, whether left or right, influence insight, future planning and motivation. If you have no strategic plan for getting better, and no motivation to develop one, your long-term rehabilitation and ultimate Quality of Life will be poor. Indeed, I have seen patients who are physically intact and relatively cognitively intact, yet are unable to function in the real world because of poor strategic planning and poor motivation, and whose Quality of Life is severely constricted.

One additional item before I move on to my next point. People with strokes in the brain stem or other infratentorial regions end up with better overall rehabilitation and Quality of Life outcomes than people with strokes in the cerebral hemispheres, even when matched for severity of physical disability. I presume that the hemispheric lesions cause related disorders of higher cognitive function, or disorders of the motivational, awareness, or strategic planning type which interact not only with the physical disability but also with the caregiver, affecting both therapy and Quality of Life.

My next topic has to do with psychological maladaptations following stroke. The first point that I wish to make is that a small percentage of people (2 percent) report a better Quality of Life four years after their stroke than before. I'm not sure how to explain this, and we might want to explore this phenomenon in future research. We have been trapped, until now, by one dominant conceptual model. The medical model in our society concentrates on dysfunction, not preserved function. As we explore Quality of Life issues in the future, I think we would be wise to take advantage of preserved capacities, to look not only at disability, but also at ability.

To understand psychological maladaptations following stroke, we might consider the following categories concerning post-stroke Quality of Life:

1) medical/physical changes

2) personality changes

3) changes in social context

4) changes in life's "purpose."

To this point, I have been addressing the medical, physical, and personality changes. Analysis of the psychosocial consequences of stroke can be understood within dynamic phases or stages of adaptation and change.

Life has changed abruptly. This is the most awful reality. I think we can all identify with that. However, research has demonstrated that most people adapt to their deficits, overcome their initial distress, and find some satisfaction in their new lives, although it may be at a lower level of satisfaction than before. Furthermore, research shows that once a degree of life satisfaction is restored, it is maintained; but if a poor level of life satisfaction is established by the end of the first year, it persists, and has been demonstrated to influence long-term Quality of Life.

In the first few weeks following the stroke, all energy is focused on the medical and physical changes. In the next stage, several weeks later, energy is directed to psychosocial issues. Active intervention of family and social support in the first three-to-six months-following stroke is critical in restoring a good level of life satisfaction and has been demonstrated to influence Quality of Life. This relates to the point I made earlier in my talk that psychological maladaptations often occur early after stroke, and if not dealt with effectively, are long-standing. With regard to communication disorders, after the first six months, the degree of aphasia and degree of physical disability are less important to Quality of Life than the level of social support.

I would like to conclude my brief talk by tying together the two principal messages I have been presenting: One having to do with the effects of brain damage on the patient-caregiver interaction and the other having to do with psychosocial consequences of stroke; and I would like to the tie them together in a way that points to future research:

Most stroke rehabilitation is concentrated on disability and not ability. Little stroke rehabilitation brings family and social support networks into the process in a way that takes advantage of the unique individual and communal interests of specific cultural groups. I think the National Institutes of Health is a remarkable opportunity to open the door to research which evaluates the rehabilitation potential of preserved strengths of the patient and the distinctive characteristics of specific family constellations and cultural groups. This may be the right time to encourage a cross-cultural, longitudinal study of post-stroke Quality of Life in various ethnic groups, in persons with and without aphasia, with an emphasis on discovering early neurological, medical, and psychosocial predictors of long-term outcome and determining resource needs of different communities.

HEALTH RELATED QUALITY OF LIFE IN STROKE PATIENTS: UPDATE ON CURRENT AND FUTURE RESEARCH NEEDS

Lewis E. Kazis, Ph.D.

Over the last two decades, substantial progress has been made in the measurement of health and functional status. New reliable and valid patient centered approaches for assessing health-related quality of life in chronically ill patient populations have been developed. While quality of life assessments have particular relevance in patients with neurologic problems, few studies have reported the health related quality of life impacts in patients with stroke.

Neurologic measures need to target implicitly the gamut of possible anatomic involvement, sensory and motor dysfunction, and cognitive impairment. Some neurologic conditions may cause highly focal abnormalities, for example such as reading or writing. Other degenerative conditions may be more generalized. Pharmacologic treatment or other therapeutic interventions may improve the signs and symptoms accompanying the illness, however the specific treatment may have other deleterious affects on quality of life.

Studies of health related quality of life in stroke patients are seriously lacking and have previously been confined to descriptive case studies, observation and some longitudinal work targeting standard clinical assessments. The aftermath of stroke may include paralysis, cognitive dysfunction and social limitations. This clearly has important quality of life implications in terms of the physical, psychological and social functioning of the patient. Some level of spontaneous recovery may be present and can range from slight improvement to nearly complete recovery. While this pattern of recovery has been reported to occur within the first six months of its onset, continued improvement over up to several years has been reported. The characteristics and disabilities associated with stroke may have specific quality of life impacts. The use of both general and disease specific quality of life assessments in stroke patients will contribute to a more comprehensive understanding of the illness burden of this condition.

The presentation will include a description of some of the more recent studies where health related quality of life assessments are used as an indicator of case mix of health outcomes. A discussion of future research needs will also be given.

disablement will be addressed. For example, clinicians can determine taste preferences for a patient with dysphagia, which in some cultures will eliminate cold foods and dairy products, or substitute certain foods of a recommended texture for others. As well, in the area of aphasia, clinicians can select a core set of functional communication icons that are culturally appropriate, or set goals for verbal communication that are not based on standard English. These and similar approaches will, as Gloriajean Wallace states, “defy the American cultural norm that the patient adapts to the clinician” and address the question, “What about the other way around?”

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